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THE UNIVERSITY OF ALBERTA

THE EXPERIENCES OF MOTHERS OF HEARING IMPAIRED ADOLESCENTS

BY

Ⓒ MELANIE J. MORGAN

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS

FOR THE DEGREE OF MASTER OF EDUCATION

IN

SPECIAL EDUCATION (HEARING IMPAIRED)

DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

EDMONTON, ALBERTA

FALL, 1987

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ISBN 0-315-41106-6

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THE UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled The Experiences of Mothers of Hearing Impaired Adolescents submitted by Melanie J. Morgan in partial fulfilment of the requirements for the degree of Master of Education in Special Education (Hearing Impaired)

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Date: June 24, 1987

ABSTRACT

The purpose of this study was to understand and to learn from the experiences of mothers of hearing impaired adolescents as the women reflected upon the years leading to and including their hearing impaired children's adolescence. A phenomenological approach was utilized to explore the experiences articulated willingly by these mothers. Five women whose children represented a broad range of ages within the adolescent years and of educational placements were selected and two interviews were held with each participant.

Six themes emerged from the detailed study of the collected data on the mothers' experiences. The themes are as follows:

1. personal growth experienced by the mothers as a result of this traumatic life event
2. relationship of the mother with her hearing impaired child
3. a variety of parent-professional relationships
4. concerns expressed by the mothers regarding educational programming
5. importance of a fluent communication methodology
6. support systems available to the mothers' growth and development.

A number of areas were identified for research which would contribute to a greater understanding of the mothers' experience with their hearing impaired children. Recommendations were made for parents, professionals, the interaction of parents and professionals, and program considerations.

ACKNOWLEDGEMENTS

I would like to acknowledge the following individuals for their support and assistance throughout this project:

- my co-researchers, the mothers of hearing impaired adolescents, for willingly participating in this study and sharing their experiences;

- Michael, for his strength and belief in me, helping me to find and maintain the balance in my life;

- my family and friends, for providing me with support and encouragement;

- my co-supervisors, Prof. L. Wilgosh and Prof. M. A. Bibby, and committee members, Prof. C. Yewchuk and Prof. J. Blakey, for their assistance, guidance and timely suggestions.

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CHAPTER I

Introduction

Few programs and little research have accessed mothers of adolescent children. The majority of the programs, research and suggestions for parents have focused upon those with infants and preschool children and although researchers and educators have acknowledged the importance of the mother in the development, functioning, and habilitative process of children and their subsequent performance in the classroom, the majority of the attention has been focussed upon the children. The mothers in this study discussed their experiences regarding the years leading to and including their children's adolescence.

Much of the research with mothers has been limited to studies examining communication and interaction styles of mothers with their children. Areas that may have influenced the women's functioning, such as amount and quality of support, the involvement of the immediate and extended family members, and perceptions of the individual herself, have rarely been included.

Mothers of hearing impaired children were chosen for this study for several reasons. They have been the primary caregivers in the family, shouldering most of the child-care responsibility, although for some two parent families this has started to change. With the increase of single parent families occurring in our society, the problems for single mothers have become more acute. The involvement of the mothers is often intensified when their children are hearing impaired.

Adolescence is a crucial time period for both adolescents and parents. For mothers with hearing impaired adolescents, this may be a time to reflect upon the past growing years of their children, the successes, failures, trials and joys. In hindsight, the women may attempt to examine the appropriateness of decisions made when their children were youngsters. Stressful parent/child relationships may be experienced at this time and the mothers must learn to cope with aging, new life tasks and the possibility of increased time for themselves and their own interests. Many mothers of disabled children have been intensely involved with their young children, but for most mothers of handicapped or non-handicapped children their involvement and responsibility for their children diminishes at their children's adolescence.

Adolescents experience stress and change in their physical, social, and emotional growth which is intensified by a disability such as hearing loss. For hearing impaired youths, the gaps in schooling, social life, and emotional and intellectual development may have become wider and more noticeable to the adolescents, the parents, and the world at large during this period.

Although much of the literature available describes the parents' emotions and stages of adjustment to their children's hearing loss, the problems encountered by hearing impaired children, and suggestions for programs, the meaning of the experiences and the effects upon the mothers have rarely been studied. Mothers need to be studied through an approach, such as the phenomenological research methodology, that allows their personal experience to be explored.

The conceptualization of what deafness has meant to mothers, fathers, children, the family unit, and society has not been explored thoroughly from a psychological point of view. Few efforts have been made to systematically observe the impact of deafness on the individuals involved (Moores, 1982). In recent years, social scientists have been criticized because of the limited nature of their method of inquiry in psychology and specifically in the field of deafness. "We must move beyond the laboratory and consider how individuals function in nontest situations" (Moores, 1982, p. 143). There have been few, if any, phenomenological studies completed involving parents, specifically mothers, of hearing impaired children or adolescents.

Through the phenomenological research methodology, an understanding can be gained by the researcher regarding a person's rationale for his/her decisions and choice of various approaches. Barritt, Beekman, Bleeker, and Mulderij (1983) stated that the value from this type of inquiry occurs from possibly changing the researcher's view that the person's actions are irrational and annoying into understanding these decisions as rational and sensible from the person's perspective.

This type of research enquiry may have many benefits. A professional educator's interest and attention to the mothers' lives may support the mothers in recognizing that their experience has been worthwhile and important. The process and involvement in the research may be cathartic for the participants. Parents who share similar life events bring an important perspective to dealing effectively with the extra demands of a disabled child, and, therefore, it may be beneficial to parents who read about other parents' experiences and suggestions, and write about their own successes and trials.

Parents of hearing impaired children have written upon a broad range of topics. In many journals and magazines, they have increasingly found a voice expressing their feelings, opinions, and experiences of having and raising a hearing impaired child. Communication has often been a dominant theme in their writing whether it has been in reference to the unisensory , oral, or oral-manual modes, or American Sign Language.

Recommendations for counseling, treatment, life improvement, and education have also been made. A compilation of information from parents and deaf adults around Canada was published by and for parents of hearing impaired children, adolescents and adults (Griffith & Scott, 1985).

This study by a special educator was intended to merge the experiences of mothers with the uncovering of meaning from their experiences by a professional. This research may contribute to the growing understanding of the importance of parents, especially mothers, in the lives of children. Many parents and professionals have been involved cooperatively on committees and boards, but few parents and professional people have had the opportunity to discuss their everyday life experiences regarding hearing impaired children. By examining the experience of the mothers, the professionals would perhaps gain an increased understanding and empathy for the parents resulting in increased cooperation with and better service for the parents. It was hoped that better communication among and within the relationships of parents and professionals would occur and that the parents, too, would be encouraged by researchers who were attentive, enthusiastic and open minded.

Definitions

The following definitions provide relevant information required to understand certain concepts as used in this thesis.

American Sign Language - a language which utilizes signs formed by hand configuration, movement, position and orientation representing concepts not words; various dialects with their own lexicon and grammar; utilizes facial and body expression (Childhood Hearing Impairment, 1984).

Bracketing - recognizing, interrogating, acknowledging and setting aside presuppositions about the phenomena through writing, identifying, and making explicit ones biases, opinions and expectations (Barritt, Beekman, Bleeker, and Mulderij, 1983; Becker, 1986; Bogdan & Biklen, 1982; Polkinghorne, 1983).

Conductive hearing loss -a loss which occurs whenever a barrier to sound is present in the outer or middle ear (Martin, 1981).

Co-researchers - the term used to describe the informants who are treated as full participants in the research process sharing with the researcher an interest in exploring the concept to be studied (Polkinghorne, 1983); the mothers of adolescent hearing impaired children in this study.

Deaf - a term used to describe a person whose hearing is disabled to an extent (usually 70 dB ISO or greater) that precludes the understanding of speech, with or without the use of a hearing aid, through the ear alone (Moores, 1982).

Hard of Hearing - a term used to describe a person whose hearing is disabled to an extent (usually 35 to 69 dB ISO) that makes difficult without precluding the understanding of speech through the ear alone, with or without a hearing aid (Moores, 1982).

Hearing Impaired - entire range of auditory impairment from mild hearing loss in which a person may understand speech without difficulty to those with a profound hearing loss (Moores, 1982).

Manual Coding Sign Systems - system such as SEE_1 (Seeing Essential English)and SEE_2 (Signing Exact English) in which a sign lexicon is grafted onto English syntax (Childhood Hearing Impairment, 1984).

Oral Communication methods - utilizes speech through maximal use of residual hearing (hearing aids), speechreading and speech teaching excluding sign language (Childhood Hearing Impairment, 1984).

Phenomenological Research Methodology - a framework of psychological inquiry that utilizes a descriptive method to explore the meaning and context of human experiences with articulate participants, or co-researchers, who are chosen to provide rich description of their experiences and to explore their experiences with the researcher. The data may be gained through interviews and is treated through a series of prescribed steps to identify common elements; this research process is dependent upon the researcher's bracketing of her/his presuppositions, biases and expectations Barritt, et al, 1983; Colaizzi, 1978; Giorgi, 1985; Polking horne, 1983).

Post-lingual deafness - condition of persons whose hearing loss occurred at an age following the spontaneous acquistion of speech and language (Moores, 1982).

Pre-lingual Deafness - condition of persons whose hearing loss was present at birth or occurred at an age prior to the development of speech and language (Moores, 1982).

Profound hearing loss - the average hearing with this type of loss is 95 dB or greater at 500-2000 Hertz (ANS); the person hears no speech or other sounds without amplification.

Sensorineural hearing loss - occurs when there are disturbances in the inner ear or auditory nerve of the ear (Martin, 1981).

Severe hearing loss - average hearing with this type of loss is from 65 - 95 dB at 500-2000 Hertz (ANS); the person hears no speech sounds of normal conversations without amplification.

Total Communication (or Simultaneous Method) - utilizes sign language, fingerspelling, hearing aids, speech, speech teaching and lipreading (Childhood Hearing Impairment, 1984).

Unisensory communication method - utilizes training of residual hearing without visual cues (Childhood Hearing Impairment, 1984).

Overview of the Study

This study was designed to explore with mothers of adolescent hearing impaired children their remembered and perceived experiences regarding the years with their growing children. A phenomenological research approach was the chosen method of study. Five mothers, considered as co-researchers, were chosen and two interviews with each participant were held to identify and understand the meaning of their experiences.

Chapter II presents the literature review which focuses upon deafness and its impact on the family, the need for parental and adolescent counseling, parent-professional relationships and educational considerations. The rationale for qualitative research, a comparison of the qualitative and quantitative approaches and a general examination of phenomenology constitute the third chapter. The methodology specific to this study will be discussed in the fourth chapter. The six themes that emerged from this study and the summary of these themes are presented in Chapter V. The limitations of the study, recommendations based on the themes and suggestions for further research are located in the final chapter.

CHAPTER II

Review of the Literature

The review of the literature provides basic background to the project. The areas of research examined included: an overview of deafness; the impact of the handicap of deafness on families; the relationship of family members with the hearing impaired child; the development of hearing impaired children and adolescents; the need for early, effective counseling; the state of relationships of parents and professionals and means to facilitate these interactions; and educational programming.

Overview of Deafness

Hearing impairment is an invisible acoustic filter that either partially or totally excludes the perception of sound. This disability primarily affects the acquisition and use of language in communication which underlies the normal development of children in all world cultures. Human beings rely on communication for most of their daily interactions, learning and experience; because of this, the loss of hearing is a devastating handicap.

Children learn language as they use language, to produce and to understand messages, and in relation to mental concepts that have been formed through experience. Communication is the exchange of ideas and information by any possible means and is the key to social, emotional, educational and occupational development. When communication is cut off or uncertain, anxiety is experienced. Having a communication disorder leads to isolation at a very fundamental level (Luterman, 1984).

Luterman stated that when he was with a group of deaf people with whom he did not share fluent communication he felt very isolated and frightened and was relieved when he met someone with whom he could speak fluently. It must be very difficult for deaf individuals to deal with the hearing world on an every day basis with these types of experiences and feelings.

A variety of methods exist through which hearing impaired people communicate. They utilize lipreading, audition, various sign systems, American Sign Language, or any of these in various combinations (Childhood Hearing Impairment, 1984)."No one solution will suit every deaf child. All deaf children will not be satisifed by the same solution to their needs, whatever they are"(Schein, 1980, p. 8). Whatever the chosen method, it must be effective and reliable.

Hearing impairment in infants and children may affect their speech, language, social, emotional and cognitive development. The hearing impaired child has an identity and personality that is distinct from, but influenced by, the disability (Ogden, 1984). While hearing children's intact auditory modality enables them to master early sound, shape and sense of language, the varied amounts of sound deprivation sharply curb and inhibit hearing impaired children's responses to language and their environment. Self-expression and understanding may be severely delayed. Impeded hearing can cause tremendous communication difficulties restricting experience, preventing optimal educational attainment and hampering personal, social and emotional development (Bloom & Lahey, 1978; Ling, 1985; Ogden, 1984).

Garretson (1981) stated that deafness may be separated into two levels. The physiological level is the inability to hear. This level has received the most direct attention because of technological advances such as hearing aids and telecommunication devices.

The other level, the psychological level, is the communication handicap resulting from the disability of impeded hearing. This level has not received as much attention as the physiological one but has a much more vital impact on the person's lifestyle (Garretson, 1981).

Many handicapping conditions are outwardly and physically obvious. A handicap, according to Garretson (1981) is defined as, "an interaction between a disability and an environment in which the design or nature of the environment creates obstacles or barriers to disabled people " (p. 14). The communciation barrier for hearing impaired individuals is the major handicap. Deafness can and does occur without other impairments and is, for the most part, outwardly unrecognizable. Unlike cerebral palsy, mental retardation and epilepsy, deafness is a low profile disorder. Those with a hearing loss are often misunderstood or miss many of the nuances with their own family and all parts of their life. The frustration of not being understood or of not understanding can affect one's development and behaviour throughout life (Childhood Hearing Impairment, 1984). The etiology, age of onset, and presence of additional conditions influence the extent the deafness hampers an individual in day to day living (Moores, 1982).

Conditions that potentially predispose children to hearing loss have been listed by the Joint Committee on Infant Hearing in 1981 and revised in 1984 by an interdisciplinary task force of otolaryngologists, audiologists, speech-language pathologists, primary care physicians, and educators of the hearing impaired under the Canadian Department of National Health and Welfare. They compiled a High Risk Register for Hearing Loss which include the following risk factors:

1. A family history of childhood hearing impairment

2. Congenital perinatal infections (eg. toxoplasmosis, rubella, cytomegalovirus, herpes, syphillis)
3. Anatomic malformations involving the head or neck (eg. dysmorphic appearance including syndromal and non-syndromal abnormaliites, overt or submucous cleft palate, morphological abnormalities of the pinna)
4. Birth weight less than 1500 grams
5. Hyperbilirubinemia at a level exceeding indications for exchange transfusion
6. Bacterial meningitis, especially Haemophilus influenzae
7. Severe asphyxia which may include infants with Apgar scores of 0-3 or who fail to institute spontaneous respiration by 10 minutes and those with hypotonia persisting to two hours of age.

The Task Force Report (as cited by Childhood Hearing Impairment, 1984) stated that use of a high risk register will facilitate the identification of 75% of children with hearing loss. It stated that 10% of all pregnancies are "high risk" and 1/50 of all Intensive Care Nursery babies may have a significant hearing loss. In pregnancies not deemed to be "at risk", one in 1,000 infants may have a profound hearing loss and yet outwardly appear physically normal (Childhood Hearing Impairment, 1984).

Deafness may result from infection or childhood diseases such as mumps, meningitis and red measles. Mumps have a five percent incidence of unilateral deafness and have been the leading cause of unilateral sensorineural deafness. The deafness may be profound and irreversible although from 10 - 25 %, in some reports, show partial recovery and a less severe loss. Meningitis has an incidence of deafness of 6 - 27 %, with the highest incidence occurring in the first year. The majority of those affected are between the ages of three months and three years and females are outnumbered by males in a ratio of 1 to 1.4 . After an occurrence of red measles, mumps or meningitis, an auditory evaluation is recommended.

Each profession, suggested the Task Force Report (Childhood Hearing Impairment, 1984), should ensure that support is available to hearing impaired children and their families. Audiologists, educators of the hearing impaired, physicians and speech-language pathologists are the four professional groups most likely to be involved in the identification, evaluation, habilitation and education of hearing impaired children. The fields of child development, education, linguistics, psychology, counseling, phonetics, acoustics, electronics, otology and genetics may also be required for knowledge and skill application. No individual profession likely possesses the knowledge or skills in all of these areas. Depending upon urbanization and geographic location, there may be overlap of professional responsibility (Childhood Hearing Impairment, 1984).

The Impact of Deafness Upon the Family

"What truly counts in life is not a matter of what is in you or me but what occurs between us. That divine spark of relationship, of a sense of family, may be the most fundamental life-force of all" (Murphy, 1979, p. 388). Studies by Bodner-Johnson (1982, 1986), Bronfenbrenner (cited in Bodner-Johnson, 1982) and evidence presented in Moores (1982), Ogden (1984), Schoenwald-Oberbeck (1984) and Simmons-Martin (1983) have suggested that parents and the home environment greatly influence the behavior and the social, cognitive and linguistic development of their children. The school, teachers, materials and peers were often the subject of study yet it is the family, the parents and siblings who have the greatest influence upon the hearing impaired student (Bodner-Johnson, 1986).

Hearing impairment greatly influences the functioning of the family unit and its members. The stresses of hearing impairment can affect the financial, marital, occupational, educational, familial and recreational decisions of the family.

Parental acceptance and a healthy parent-child relationship can have a significant influence on the later well being and achievement of a deaf child. The child's situation can be affected by a variety of factors such as the personalities of those involved, the family's values and structure, social and economic factors, the child's hearing loss, the ways parents responded to the hearing loss and the discovery that the child was not the perfect child of their fantasies. Children become socialized members of society through a complex process that involves ongoing interactions with a wide range of individuals and settings (Moores, 1982; Ogden, 1984; Stein & Jabaley, 1981).

In an account of his life, Pettingill, a deaf man, described how he at first drifted away from his hearing family but in later years asked for and received enthusiastic assistance from them. His family members and Pettingill regretted not knowing and helping each other throughout the interim years; they had not realized that knowing and associating with deaf adults would have helped them understand deafness and his future. The family can play an important role and provide powerful support for deaf people of all ages. If parents, family, and deaf adults teamed up, communicated, and worked together closely, a strong power base could be formed (Pettingill, 1984).

Family members are often faced with the inadequate understanding and intolerance of society for people who deviate from the norm. Society places a stigma upon deafness and other handicapping conditions which may seriously affect the functioning of the involved person and her/his family. The parents may be viewed by others, or view themselves, as having a serious deficiency when they have a handicapped child. "If I am good I shall be blessed with a perfect baby. The baby is not perfect therefore I must be bad" (Garguilo, 1985, p.16). This adds tension to an already stressful situation.

Duvall has observed that the family unit develops through seven stages which includ: a childless married couple; a childbearing family; a family with preschool children; a family with children at school age; a family with adolescent children ; a family with young adults leaving the home; and an aging family (Duvall, cited by Moores,1982). The greatest adjustment of the family, as stated by Moores (1982), is from the childless to the childbearing stage. Some of these adjustments occur because the birth of children disrupts routines, modifies values, limits the family income from possibly two to only one income, and entails redistribution of the attention of the family members. When a family moves from one stage to another, the functions and roles of each member changes which can cause greater tensions and an increased possibility of role conflict, and family breakup may have occurred. The presence of a handicapped child may tend to exacerbate the normal family tensions and hinder a smooth transition from one stage to another.

Garguilo (1985) stated that the family of a hearing impaired child must contend with the same developmental tasks encountered by the majority of families but they must also struggle with prolonged or extraordinary demands. The family's ability to deal with developmental requirements depends on the type and severity of the disability and the availability of resources for the family (Garguilo, 1985).

Parents hold expectations for their children before and after their children's birth. Parents may view children as having represented a composite of themselves, other children and relatives or as a "gift", a way to strengthen the marriage, a way to live vicariously or to become immortal (Garguilo, 1985; Mindel & Vernon, 1971). One of the greatest fears of parents is the fear their child will be severely handicapped (Blacher, 1984).

With suspicions and confirmation of their child's handicap, parents may not know if their child will be self sufficient and productive in society or if their child will be a lifelong burden draining their emotional and financial resources. Only one-half of one percent of the population are affected by hearing loss and nine of ten hearing impaired children are born to hearing parents (Carver, 1984) therefore the majority of parents are unfamiliar with hearing impairment and unprepared to cope with a hearing impaired child. The deaf child creates uncertainty and brings into question the future goals and expectations of each member of the family unit. The fantasies and dreams of the parents' perfect child may have been shattered and they usually experience a wide range of emotions.

Several parents have described and published their experiences with their hearing impaired children. For example, one parent, Nastoff (1986), poignantly wrote:

> Parents fight the unseen enemy. We have reason for revenge but nothing against which we can vent our rage. Our children are held hostage by a cruel twist of fate...It is in the air all around you every moment of your life, overshadowing all decisions about your child, crushing and destroying the simple parental right to dream... I can feel the enemy now, its fingers tightening at my throat...sometimes it loosens its painful clasp but never does it desert its hold on my life...Professionals can say what

> they like about proper amounts of time for denial, distress and bitterness, but when you have a constant struggle, a lifetime responsibility to face shattered parenthood dreams take years to repair...a precious part of my life has been disrupted. It's irreplaceable and irreparable (p. 43).

Another parent, Kulakowski (1984), described his reactions to his child's deafness, "the first reaction was grief, sadness and a hurt like I had never known before. The hurt never really goes away. You learn to live with it but the sadness lingers just below the surface. Little things bring it back" (p. 11).

Two books, Deaf Like Me by Spradley and Spradley (1978) and Speak To Me by Forecki (1985), are moving accounts of the experiences of being a parent of a deaf child. The former book is written by the hearing impaired child's father and sibling and the latter by the mother. The authors were remarkably candid about their lives presenting their struggles in raising their children. They described the day to day activities, the more traumatic or important events and the steps they took, sometimes uncertainly, through which to cope. These books provided a strong personal account of the educational and philosophical differences within the field of deafness. Both books stressed the need for fluent two way communication in a home filled with love. The authors still have questions regarding the educational, social, communicative and employment opportunities of their children.

Platcow (1983), another parent, described objectively and candidly the growing years of her adult deaf daughter, Ruth. Ruth's struggle in life, according to her mother, was to learn to adjust in a hearing world while Platcow attempted to accept the reality of her daughter's handicap and the accompanying special needs. Platcow had treated her daughter as 'normally' as possible but, as she noted in later years, Ruth was not like everyone else and did have special needs. Since Ruth has had her own family and career, mother and daughter have discussed the frustrations and struggles Ruth had dealt with, of which the mother had been unaware. Ruth is now, however, content that she has worked hard and followed that route. Shared, fluent communication at an earlier time might have spared them some of the struggle and inner frustration both had felt. The effect upon the families and each individual member in the family unit is thus profound.

A great deal of the research literature has examined the process parents experience in learning to adjust to the trauma of their child's hearing loss. The next section will present several types of categorization systems designed in an attempt to explain parental adjustment to deafness.

Four periods of extreme stress for the family unit have been proposed, the first of which is the process of identifying the loss (Moores,1982). The second period of family unit stress occurs when the child enters school which is the first substantive role change for the deaf child. The third period of extreme stress involves the child's adolescence and the last of the stressful times is early adulthood (Moores, 1982). The majority of the research has been focussed upon the first two periods of extreme stress.

Initially the parents and family may have reacted to having a disabled child by marshalling their resources. As they realize the problem is long term, the unity of the spouses perhaps may begin to wear. Hearing impaired children may have become a symbol of shared failure evoking strong emotions in both parents; this could become a fertile area of conflict disrupting the organization of the family (Luterman, 1984).

There has been some discrepancy in the literature regarding the stages of adjustment. Blacher (1984), who reviewed a variety of stage theories for a population other than that of hearing impaired individuals, suggested that there is considerable variation in the timing, duration, and behavior within each stage, which may have been an artifact of the various methods used by the researchers to determine the variations in the number, description and causes of the stages. The definitions of the stages and whether each stage is time, culture or person related, and the rate and applicability of a model to a group of people have also been questioned. Some researchers, cited by Blacher (1984), stated that parents do not go through an ordered sequence of discrete stages of adjustment and may not reach the final stage of acceptance, however, feeling positive in the step by step movement towards acceptance. As well, unresolved, contradictory feelings may hinder the parental adjustment progress.

Blacher in her review of works completed by other authors concerning handicapped populations identified three different stages which included: initial crisis; emotional disorganization; and adjustment, acceptance or emotional organization responses. The first response of the initial crisis may last from one day to several years and is experienced with a variety of emotions. The second response, called emotional disorganization, is the stage of a wide range of emotions and reactions such as guilt, disappointment, anger, lowered self-esteem, resentment, aggression, hopelessness, or detachment, and physical symptoms such as insomnia or a depressed appetite. The last response period is adjustment or acceptance, characterized by emotional organization. This latter response has sub-stages of reconstruction, reorientation, and acceptance. Parents may focus on problems outside of the home, access programs and services, and become involved in advocating for their children channelling their energies into solving realistic problems and develop love, acceptance, warmth and attachments.

Featherstone (cited by Luterman, 1984), a parent of a severely disabled child, stated that she was "uncomfortable with most stage theories, they carry too heavy a freight of straight line progress; they also suggest an implausible final harmony. The actual progress is not linear, and often is bought at a high price in human suffering...Few parents reach an emotional promised land; most have good days and bad days" (p. 26). A great deal of the research has centered upon these stages which, although seemingly inadequate from a parent's and another researcher's point of view, attempt to explain the parents' abilities to cope, as best as possible, with the trauma experienced with a hearing impaired child.

Ogden (1984) stated parents of hearing impaired children must go through a cycle of adjustment although some parents may become fixated at one point. In the research, two other types of parental adjustment processes have been described which will be presented. One type is based upon a prediagnosis and diagnosis time frame (Mendelsohn, 1981) and the other upon the emotional reactions of the parents (Luterman, 1979; Moores, 1982; Simmons-Martin, 1983).

In the periods of adjustment based upon the time frame model, parents of hearing impaired children are said to experience two phases, the first phase of which is the prediagnostic phase and the second, the diagnostic phase (Mendelsohn, 1981). In the prediagnostic phase, parents may have had an ill defined feeling or uneasiness about their child possibly caused by the few outward symptoms in young children that indicate hearing problems. The parents may have felt 'empty' when the child did not turn and smile at the parent's voice and the child been viewed as exhibiting negative behavior instead of displaying a physical symptom. Parents sublimate their fears and become more involved in outside activities. They may have felt as if they were 'bad' or were irrationally or excessively worrying about their child. From the time of the hearing impaired child's birth a potential crisis has existed for the spouses. Their anxiety about their child may cause them to self doubt and/or to blame each other leading them to become isolated from each other, and to further denial of symptoms. Once the hearing loss has been confirmed, parents enter the diagnostic phase(Mendelsohn, 1981).

After the diagnosis of deafness, parents may initially feel relief that their anxiety is over and their worries confirmed but this is quickly followed by overwhelming complications. The second type of parental adjustment described in the literature, the emotional reactions of the parents to their children's hearing loss, includes and expands upon the diagnostic phase (Mendelsohn,1981) of the time period framework.

The parents' emotions during and after diagnosis are very intense. A wide range of responses may occur as the parents mourn the loss of their 'perfect' child. Some parents of disabled children have warm, protective feelings and others may feel threatened, uncomfortable or even repelled. The discrepancy between the parents' expectations and reality poses a major hurdle for the coping abilities of the parents (Featherstone, cited by Blacher, 1984; Garguilo, 1985; Ogden, 1984).

Many authors have delineated a broad range of parental emotions included in these stages of adjustment. Parents often do not feel the same emotions at the same time or may be unwilling to share their emotions with each other (Luterman, 1984). It is difficult to predict the types and/or degree of reactions that each parent will experience.

Parental denial, which is a coping mechanism based on feelings of inadequacy, should be seen as a plea for help and not as a dereliction of duty by the parent (Luterman, 1984). They may be confused by the new jargon, content and information with which they must suddenly deal and may feel all alone with the problems of their children (Locke, 1977).

Both anger and guilt may be experienced with perhaps anger being the most potentially destructive emotion in a marriage. Parents may be angry over the loss of control over their lives and the violation of their expectations of the child and of themselves, and experience frustration because they have a child who is 'hurt' and are unable to do anything about it. Without an outlet, one's anger may be displaced onto the spouse, child or professional. Parents may begin to fight about inconsequential things when in fact, they feel they have lost control or are impotent because of the disability (Luterman, 1984).

Guilt, defined by Luterman (1984) as anxiety plus a sense of badness, may breed resentment and is a strong emotion experienced by the parents which must be dealt with and recognized effectively or it, too, may be destructive. Depending on the cause of deafness, the mother may feel more guilt because she carried the child during pregnancy. A study of 34 natural and 10 adoptive parents of hearing impaired children, who voluntarily completed an initial questionnaire and then a survey after watching a film, demonstrated that both groups of parents experienced much the same emotions although greater feelings of guilt and depression were reported by the natural parents (Crittendon, Waterbury & Ricker, 1985).

The extremely dedicated parent may try to make it up to the disabled child or become so involved in searching for services and groups that less attention is available to the spousal relationship, the siblings and to the parent's own needs (Locke, 1977; Luterman, 1984; Ogden, 1984).

Loneliness is one of the most pervasive attributes of parents who have disabled children, according to Featherstone (cited by Luterman, 1984). She stated, "The two most prominent ingredients of a parent's loneliness are difference, his own and the child's, and isolation. [The child] is marked in some important way, even if the difference is not immediately apparent. His mother, father, sisters and brothers live in a family that reflects that difference; their consciousness of difference makes them feel very much alone on some occasions. Failures of other people to understand their special concerns intensify the problem" (p. 42).

The stages outlined in the research may also include despair, shock, sadness, rejection, grief, blaming, depression, anxiety, helplessness, ' hard work ethic', overprotection, overindulgence, constructive action, and eventually, adjustment and acceptance. The parents may try to 'bargain' with doctors or God for the miracle cure or they may 'shop' for professionals for a diagnosis or advice (Childhood Hearing Impairment, 1984; Crittendon, Waterbury & Ricker, 1985; Garguilo, 1985; Jabaley & Stein, 1981; Locke, 1977; Luterman, 1979; McCay, 1971; Mindel & Vernon, 1971; Moores, 1982; Ogden, 1984; Schein, 1980; Simmons-Martin, 1983).

Parents ride an emotional and psychological rollercoaster while also attempting to learn the technical nature of the handicap (Simmons-Martin, 1983). The stages, viewed as fluid and nonexclusive, are passed through by the parents as their individual adjustment process allows. The magnitude of the parents' feelings and reactions reflects their perception of the problem. With time and experience, the parents may become more adept at coping with and proceeding through the various stages. They may feel caught in a dilemma of wanting to care for and to abandon the child at the same time.

Few researchers view these periods of emotional adjustment as a positive or adaptive process, however, these emotions are natural and can be a cleansing process in which each stage is necessary (Ogden, 1984). These emotional reactions are part of a long term coping process. The desired outcome of the denial, mourning and anger of the parents is the development of meaningful, mutually satisfying communication between the deaf infant or toddler and the parent (Greenberg,1983). Parents must work through their grief to the mature acceptance of their deaf child for psychological and social development and deal with the outer reality of a child with a hearing loss and the inner reality of adjusting to the loss of a desired normal child. Having worked through each crisis in a rational manner, recognized their emotional reactions, and developed a sense of their lives as a series of difficult and less difficult stages, parents may reach their level of coping and adaptation (Bodner-Johnson, 1985; Moores, 1982).

Often more devastating and irreversible than deafness is the involved professional's errors, omissions, misinformation, false hopes and lack of knowledge (Haas and Crowley, 1982; McCay, 1971). Much responsibility lies with those who have met with the parents and who have attempted to assist the family to cope. The frustrations of the parents may be compounded because the 'expert', usually the pediatrician or family doctor, is not trained in deafness nor appreciative of the parents' anxieties. Parents may feel that they do not want to waste the doctor's time or that their questions are too insignificant to relate to the expert (Mendelsohn, 1981). Early diagnosis, which seems contingent upon the astuteness and persistence of the parents, and coping may foster effective development of the family and child (Haas and Crowley ,1982; McCay, 1971).

A study by Haas and Crowley (1982) examined parents of preschool children and their view of the information dissemination by professionals. Sixty-five sets of parents answered a twenty-five item questionnaire concerning the effectiveness of certain members of the medical profession, audiologists, speech-language pathologists, and educators of the hearing impaired in providing information. The parents were usually the first to suspect a hearing loss, followed next by the grandparents. In only seven percent of the cases were doctors the ones to alert parents with their suspicions of the child's hearing loss. The most meaningful input concerning the implications of deafness was overwhelmingly provided by the educators and it was the audiologists who were chosen the most effective in disseminating information. The parents' answers indicated that those in the medical professions were the least effective in providing information about the nature and degree of hearing loss, yet often the pediatrician was the family's first contact. Incidents were reported by parents in which they were told by their doctors that they were overly anxious and generally incompetent and that the child would probably soon be talking (Haas & Crowley, 1982).

The delay between the parents' suspicion of hearing loss and a professional confirmation ranged from three months to more than two years (Haas & Crowley, 1982). Moores (1982) found the average delay in time of diagnosis is one year. The delay is greater for mild to moderate losses. The number of professionals involved in the service delivery system has been deemed an obstacle to early diagnosis and intervention. As the child grows older it becomes easier to diagnose a hearing loss, but in the first eighteen months there is a substantial lag from the time of the parents' suspicions to diagnosis. The more severe the loss the easier it is to diagnose (Haas & Crowley, 1982). Two reasons were suggested by Stein and Jabaley (1981) to account for the delay and inefficient diagnosing of deafness by the pediatrician. These were: their lack of awareness and knowledge of deafness; and the lack of one definitive test for testing the hearing of infants.

Early diagnosis of deafness may have assisted parents to accept their child. Often parents complained of a delay in diagnosis which caused Stein & Jabaley (1981) to speculate whether this interfered with the development of a healthy relationship with their children.

The Relationship of Parents and Their Hearing Impaired Child

The parents' feelings may interfere with the development of a warm, stable relationship with their hearing impaired child. Parents may become less responsive and sensitive to their child's needs and may withdraw from their child. Simmons-Martin (1983) observed that parents sometimes found it difficult to spend time with, play with, talk to or interact with their deaf child. Language development for most hearing impaired children is usually delayed which may increase the parents' anxiety. One parent, usually the father, tends to withdraw from the family, immersing himself in his work, while the mother will usually take the role of expert becoming completely involved with the hearing impaired child, thus, the father enters a less than ideal situation from which to make the decisions, and in a family with a traditional definition of sex roles, this could cause innumerable difficulties (Carver, 1984; Luterman, 1984; Schlesinger & Meadow, 1972; Stein & Jabaley, 1981).

The literature has suggested that there are differences between the development of the hearing impaired child with hearing or deaf parents. Stokoe and Battison (cited by Harris, 1982) and Carver (1984) stated that there is likely a lower incidence of emotional/behavioral problems in hearing impaired children when they have two deaf parents perhaps because of early and well established communication with their deaf children. " A shared language enables the transmission of social norms, personal needs, fears, and reassurances and having a role model in the family " (Stokoe &Battison, cited by Harris, 1982, p. 10). Deaf children of deaf parents have been observed to be relatively more mature, to have better interpersonal skills, self acceptance, to be better achievers and more internally controlled (Carver, 1984; Koelle & Convey, 1982; Meadow, 1980). Deaf adults as models from a young age may have assisted in the development of the children's positive feelings of self. Although deaf parents seem to more quickly and effectively deal with the deafness of their child, deaf parents, too, have experienced the shock of having their child diagnosed as hearing impaired (Ogden, 1984).

Communication

Parents can be classified, according to Nash and Nash (1981) on the basis of: 1) the parents' attitudes toward using a sign method with a systematic set of language-like rules; and 2) their evaluation of the deaf experience. Parents have varied from complete reliance on speech reading and speech production to the use of signs only or with lip movements or speech based techniques. They have evaluated their experience from accepting it as a unique but normal way of life as part of the deaf community to placing a stigma on a hearing loss. Parents who have utilized the oralist philosophy generally are said to feel that manual communication is irrelevant to their own personal and family environment; whereas the signing parents have used some type of manual communication system with or without supplementary oral communication. Some oralist parents and signing parents agreed, for example, that mainstreaming was a viable option for their children whereas other parents in both of these groups disagreed with that concept. There is no complete separation between the parents who used the oralist method or ones who used the signing approach. Nash and Nash (1981) concluded that simple categorization of parents as signers or as oralist parents was insufficient. Opinions and beliefs can vary greatly even among parents who have chosen similar communication routes. All the factors of the situation and the family must be considered when discussing the communication methodology.

Much research has been conducted on parent-child communicative interactions. Several studies cited in Simmons-Martin (1983) concluded that mothers and deaf babies follow normal developmental trends, however, other studies also cited have countradicted this belief. The latter studies stated that the interactive process of mothers with deaf children is affected by hearing impairment. These results, cited in Nienhuys, Horsborough & Cross (1985), Schlesinger & Meadow (1972) and Simmons-Martin (1983), concluded that mothers of deaf children generally use a more restricted language style with hearing impaired children than with hearing children and are: less permissive, more intrusive, didactic, inflexible and authoritarian, have a narrow range of discipline and feel frustrated with their communication, tend to dominate conversation, have less syntactically and cognitively complex speech and an unclear perception of their child's conversational level. These interactive patterns affect the development of children's language and conversational skills.

A number of negative social outcomes may result due to early communication deprivation and lack of fluent two way communicative exchanges. According to Greenberg (1983), disturbed and fragmented communication, isolation within the family, high parent stress and high rates of psychiatric disturbances may result from lack of communication in the early years. Most deaf children experience delayed language acquisition. Difficulties in communicating future plans and internal feelings and thought, dealing with qualities of objects and their abstract relationships, and imaginary play may lead to limited social interaction. Frustration may be experienced by the children and parents. These linguistic features contribute to the decreased and constrained nature of the social interaction of deaf children (Meadow, 1980). Platcow (1983), a mother of a deaf child, stated that, "deaf people like all humans need to communicate in whatever way is best for each person and to find a place in the world where each one belongs " (p. 7).

The quality of adolescent interaction depends upon the proficiency level of the communication skills attained, their own perceptions of those communicative skills and their personal-social adjustment in the communication situation. Communication is an interpersonal interactive process. Some deaf adolescents will choose to be essentially bilingual in using spoken and sign language while many will be essentially monolingual through spoken or sign language (Pronovost, 1978).

Marital Relationship of Parents

The marital bond of husband and wife appears to be affected by handicapped children although there was no consensus in the literature as to its effect. The divorce rate for parents of deaf children has been fairly high (Carver,1984; Harris,1982; Locke, 1977), but it is unclear whether families with deaf children have a higher rate of divorce than those without hearing impaired children (Luterman, 1984). A study cited by Moores (1982) found no difference in the divorce rate for parents with or without deaf children. Mother and father may lose their identity as parents and spouses if they become "teachers" which causes additional stress and tension in the family unit (Locke, 1977; Schlesinger & Meadow, 1972).

Relationships of Parent to Parent

Support of parents by professionals, as well as by other parents, and/or family members is emphasized throughout much of the literature (Garguilo,1985; Hines,1982; Kulakowski,1984; Locke,1977; Luterman, 1984; Mendelsohn,1981; Stein & Jabaley,1981). Parent groups, organized by parents or sometimes with the assistance of professionals, are an important vehicle for sharing feelings, providing mutual support and processing information. Among these parents a special relationship is established that transcends any parent-professional relationship. They have the instant understanding and rapport that occurs among people who have experienced similar life events.

One drawback of parent groups is described by Locke (1977) who stated that parents may latch onto other parents, deaf adults or professionals who are not counselors but who advise the parents on what is best for them. This advice may or may not be appropriate or healthy for the parents and their unique situation.

Advocacy of Parents

Many parents campaign for rights and educational and social services for themselves and their children. Parents who take an advocacy role require a positive image; knowledge of rights and responsibilities and resources; an ability to learn new skills and work as a team member; persistence and great understanding, tact and diplomacy (Fairchild, 1980). Advocacy can help wade through the maze of confusion and bias that faces disabled citizens but many parents burn out because of the lack of reward and assistance in their struggle for their children. It is often a lonely fight. Parents also fear reprisals. The disabled community in which they must live and work is very small and people are known. Fairchild emphasized," We must address the very real fears of parents that their children will feel the sting of revenge if [the parents] are too vocal or rock too many boats " (p. 1009).

Siblings

Mendelsohn (1985), a parent of a deaf child who became a professional in the field of deafness because of the services, or lack of services received by her and her child, stated, "When I think how difficult it was for my husband and me to cope during the prediagnostic unknown period and the period immediately following diagnosis, how did a five year old [hearing] child view it and cope with it? Why did we assume that he took it all in? We, as adults had difficulty accepting the idea of a deaf child, how did we think a five year old kindergarten child would understand?...we forgot the sib!" (p. 7).

Little attention is often paid to the relationship between hearing and deaf siblings although much is paid to hearing aids, speech or sign systems. Siblings may act as interpreters to their hearing impaired brother or sister and may become their intermediaries with the world. They play an important function in the family (Murphy , 1979). Siblings act as confidants or critics, being tolerant and taking their duty seriously. They learn from each other, share resources, and friendships; they may attempt to protect each other, act as a buffer between each other and the parents or the world making life more simple or complex (Griffith & Scott, 1985; Mendelsohn, 1985; Murphy, 1979). "The hearing sibling is often old before his time because of the responsiblity placed on him [as interpreter, caretaker,etc.]. Do you wonder that as our children grow into adulthood there is often an estrangement among them? The hearing sibling might be relieved to leave the family and lead his own life" (Mendelsohn, 1985, p. 8).

Parents often expect the sibling to be supernormal. They may have placed unbearable burdens and expectations on themselves and their other children by trying to make their lives as normal as possible and overcompensating (Mendelsohn, 1985).

The siblings may remain silent and repress their feelings of anxiety and resentment (Murphy, 1979). Expression of any of their feelings of guilt, anger or other emotions may be difficult and kept to themselves (Griffith & Scott, 1985; Luterman, 1984; Murphy, 1979). They may feel jealous of the hearing impaired child's demands upon the parents' time. Siblings, may in fact, have felt guilty that in some way they had caused the disability to their hearing impaired brother or sister. Griffith and Scott (1985) stated that the siblings generally have accepted the hearing impairment of an older sibling better when the deafness has always been a part of their life. Siblings may have an especially difficult time if they were close in age to the hearing impaired child (Griffith & Scott, 1985).

The siblings, however, have received less positive attention than the disabled child and less of the parent's energy. Within the family, the siblings may feel less important and valued. Although studies conducted on families with other handicapped children have found that the presence of a disabled child may be disruptive for their normal siblings (Moores, 1982), the possibility exists that this is the same for the hearing impaired population.

"Deaf children are watched over, scheduled and sat with and ordered for, all through their school age years... maybe we can learn from hearing children to make deaf children independent and spend more time with hearing children " (Mendelsohn, 1985, p. 9). Some siblings, however, do benefit from having a handicapped sibling becoming more tolerant, compassionate and aware of prejudices (Murphy, 1979). More research is needed on the siblings of these children.

Grandparents

Grandparents are another component of the extended family who have often provided support to or required attention from, their children. Grandparents may be a source of great comfort by providing emotional support or babysitting . Grandparents may become a beneficial part of the habilitative process and be more aware of the situation than their children believe them to be. With the knowledge that their own child is suffering and that they have a disabled grandchild, grandparents have had difficulty accepting the diagnosis and have become fixated in a denial stage. If the grandparents did not support the parents' habilitative efforts or if they needed or wanted to be cared for, the grandparents can be draining on their children (Luterman, 1984).

Emotional Development of Hearing Impaired Children

A discrepancy has existed in the literature regarding the incidence and severity of the social and emotional functioning problems of hearing impaired children in school (Stein, Mindel & Jabaley, 1981). The types of problems and the tolerance by people to identify or deal with the students has varied widely. In the past, children with emotional and/or behavioral problems have not been readily identified as needing help because there are few facilities for treatment and few professionals trained for this. It is a neglected area (Schein, 1980).

Cole and Shade (1985) studied the social/emotional adjustment of eight integrated hearing impaired adolescents compared to eight hearing students on the measures of social adjustment, self image and emotional adjustment; there were no statistically significant differences according to hearing or sex although certain patterns might have emerged had a larger sample been taken (Cole & Shade, 1985).

A wide range of emotional disturbances, behavior disorders and vocational rehabilitation problems exhibited by people who were hearing impaired has been noted (Harris, 1978). An estimation of the prevailing rates for emotional and behavioral disorders of hearing impaired children has been 10.65% to 31.20% (Schein, 1980). Studies illustrating the prevalence of behavior problems in hearing impaired children probably list rates that are below the actual rates (Meadow, 1981). Serious emotional problems were estimated as three to six times more common in deaf children than in hearing students and that one to three in ten deaf students were estimated to have a significant emotional problem (Schein, 1980).

Two of the most common factors in the deaf children's environment that would account for their emotional and behavioral difficulties have been: their lag in language development and its accompanying effect on the socialization and communication with the family; and the parents' psychological response to the diagnosis of their child's deafness (Stein & Jabaley, 1981). Bodner-Johnson (1985) suggested the probability that the quality of social psychological family environment influences the academic achievement of students. Studies cited by Harris (1982) illustrated the communication deficits in deaf persons tend to lead to problems in the personal, social, emotional and vocational areas.

Harris (1982) suggested that the prolonged dependence of deaf children on their family, educators and rehabilitative specialists may foster immaturity, insensitivity to others, egocentricity, high rigidity and a demanding attitude. Deaf children may become overly dependent on a parent, usually the mother, which can cause relationship conflicts of the mother and child with the other family members.

Many studies conducted over 40 years, cited in Meadow (1980), have concluded that deaf children tend to be less socially mature and have more adjustment problems than hearing children. Deaf children may have inaccurate or inflated ideas of their self and their capabilities and of others' opinions of them. Deaf children without serious overt problems have exhibited rigidity, egocentricity, absence of inner controls, impulsiveness and suggestibility. Hearing impaired children have demonstrated poorly developed abilities to understand and accept others' feelings, inadequate insight into the impact of their behavior on others, an egocentric world view; the inability to handle tension, reflected in their impulsive behavior and absence of thoughtful introspection (Schoenwald-Oberbeck, 1984).

Harris (1982) stated that impulse control was a major component of emotional, behavioral and vocational problems in the deaf population. In a study conducted on impulse control, deaf children of deaf parents obtained significantly better scores on the majority of the tests used, followed by the manual, oral and oral-gesture groups. Cohen (1978) stated that deaf adolescents have impulse control problems due to lack of language that allows for channelling of frustrations and aggression.

Many studies have found that individuals with a higher self concept tend to be more internally controlled (Koelle & Convey, 1982) and better achievers have tended toward higher self concepts. People with a more external locus of control have attributed their behavior to forces outside of themselves such as fate, luck or a higher power, while those with an inner locus of control would readily assume responsibility for their own behavior (Luterman, 1984). A study conducted by Dowaliby and associates in 1983, (cited by Luterman, 1984), studied 267 hearing impaired students and a control sample of 100 normal hearing students by administering a constructed learning style inventory test to measure internality, externality and people orientation. The results of the study indicated that the hearing impaired students were substantially more external in their locus of control than were the hearing students. This is consistent with the results of other studies (Bodner-Johnson, 1986; Koelle and Convey,1982).

Luterman (1984) suggested the finding of an external locus of control in disabled populations is not surprising because others in the lives of the disabled are often viewed as more powerful than themselves and they feel that the control of their lives does not reside within them. Professionals and family members who 'rescue' the deaf person are helping the deaf person to maintain this attitude of external control.

Another area of concern for the social identity and development of deaf children has been that they might have felt pulled to join or become immersed in the deaf and/or the hearing cultures (Johnson, 1984). Both cultures make strong claims on the deaf children causing the children to have ambivalent identification with both worlds. These children have been faced with difficult linguistic and cultural issues (Johnson, 1984). The family, too, may struggle between accepting the hearing and deaf worlds. Some deaf children or adolescents will enter the deaf world, some will avoid the deaf world and some may attempt to enter both worlds. Problems multiply for the family unit when the parents reject the deaf world the deaf child has accepted, or the deaf child forsakes family and the hearing world (Schlesinger & Meadow, 1972).

Although there are consistencies in the findings of the personality studies, one cannot conclude that there is a 'deaf personality type'. Much diversity among deaf people exists, related to education, communication and experience (Meadow, 1980).

Development of the Hearing Impaired Adolescent and Adult

Adolescence is a time of marked change in the physical, emotional and social development of the person. Relationships in the family life, peer group and school or work involvement have changed in the adolescent's world (Neyhus & Austin, 1978). Most deaf adolescents have had normal pubertal development and statural growth with increases in height and weight, hormonal and sexual development. During adolescence profound biological, psychological and social transformation occurs which requires adolescents to significantly restructure their relationships with the world and the people in it. Adolescents must begin to see a role for themselves in the larger world (Cohen, 1978).

The basic needs of deaf adolescents do not differ from those of hearing peers but communication problems and the variety of educational settings make it more difficult to reach satisfactory goals essential to independent living, one of the main components of the adolescent experience as one becomes increasingly independent from family, especially parents (Bonham, Armstrong & Bonham, 1981; Griffith & Scott, 1985; Lane, 1978; Marks & Cohen, 1978). Handicapped adolescents may experience greater difficulties establishing a reasonable degree of independence from parents and may enter into adolescence involved in a dependent relationship that is resistent to change (Marks & Cohen, 1978). Disabled people may live with marred physical images that impinge upon their sexual identity and may face significant limitations on career choices. They need special understanding and patience from family, teachers and peers to help the individual through confusions and anxieties (Marks & Cohen, 1978).

At adolescence, teens must face a variety of new tasks and concepts which together contribute to stable adult identity or self concept but which may take longer than the adolescent years to complete (Marks & Cohen, 1978). Included in these have been: feeling at ease with the gender role and sexuality; accepting one's maturing body; formulating a place for one's self as a contributing member of society; getting along with others; developing a philosophy of life; planning for the future; developing intellectual skills; utilizing values and an ethical system; achieving socially responsible behavior; achieving more intensive relationships with peers; gaining economic independence; separating from family (Bonham, Armstrong and Bonham, 1981; Lane, 1978; Marks & Cohen, 1978).

The deaf adolescent often does not possess some of the important tools of communication that assist hearing peers to negotiate with the teen years (Bonham, Armstrong & Bonham, 1981). Communication with hearing parents may be abrupt and limited during normal conversation but may tend to become exaggerated and problematic with the increased frequency of conflict in adolescence. Many hearing impaired adolescents are isolated from other deaf people and lack the verbal and/or manual communication tools and techniques to exchange information and meet their needs for meaningful relationships (Bonham, Armstrong & Bonham, 1981). Parents should be accepting of their children's deaf friends, the deaf community and manual communication if chosen by their deaf child (Cohen, 1978).

At adolescence, parents may try to bind their child closely to the family in hopes for a delayed miracle. Parents may maintain that their deaf child will someday be 'normal'. With the advent of their children's vocational, educational, and marital choices, parents may again have to confront their perceptions that their child will live 'normally' in the hearing world. This may lead to frustration, resentment and hostility to professionals (Moores, 1982; Schlesinger & Meadow, 1972).

Adolescents may start putting unreasonable demands on parents and self and begin 'testing'. Sleeping and eating patterns may be a cause for conflict with parents. The teens may continue to rely upon their parents to interpret for them when it should become the adolescent's responsibility. Deaf students may make tentative choices because of the continuing uncertainty of future goals (Griffith & Scott, 1985; Marks & Cohen, 1978).

As young adults, some deaf individuals may have become separated from the protective situation of school and may find they have no identity in the world. They may show an increase in impulsiveness, dependence, and conformity and strongly require structure. If they do not have internally controlled behavior and motivation, this can be a traumatic time. They may have superficial relationships and repetitively change jobs and they may be without a strong commitment to goals or to work (Kennedy, 1978; Schlesinger & Meadow, 1972).

Deaf individuals do adapt well to their world becoming productive members of society. Despite the effects of deafness on learning and adjustment, many hearing impaired young adults attain a level of social, emotional and vocational maturity needed to survive (Neyhus, & Austin, 1978).

Further research is required upon all aspects of adolescence and the functioning of deaf teenagers and young adults. As well, the experiences of those people affected by emotional/behavioral problems and the other traits common to this population must be examined.

The Necessity and Importance of Counseling

"We have learned not to stunt a child's growing body with child labour; we must now learn not to break his growing spirit by making him the victim of our anxieties " (Erik Erikson cited in Garguilo,1985, p. 41). Because of the influence of the family, and more specifically the parents, upon the deaf child's emotional, linguistic, social and academic stability and growth, the psycho-emotional and cognitive needs of the parent must be addressed (Dee, 1984; Garguilo, 1985; Henniger & Nesselroad, 1984; Luterman, 1979). Each parent requires attentive and empathetic listening, and constructive planning and extended family, health, medical, educational and vocational planning professionals play an important supportive role (Mendelsohn, 1981). Parents, children and other family members must be a focus of the habilitative process of their hearing impaired children.

Counseling of Parents

One suggestion that has occured repeatedly in the literature has been the need for counseling of most parents of hearing impaired children (Dee, 1984; Garguilo, 1985; Greenberg, 1980; Griffith & Scott, 1985; Locke, 1977; Luterman, 1979; Simmons-Martin, 1983; Williams & Darbyshire, 1982). Counseling should be provided in individual or group sessions once diagnosis has been made.

In Canada, parent counseling was reported in the 1984 Task Force Report (Childhood Hearing Impairment, 1984) as being available in the home environment in the rural and urban settings in Ontario, Prince Edward Island, New Brunswick, Nova Scotia and Newfoundland and was often available in the urban areas of British Columbia. Parent counseling in a hospital or clinic setting is always available in most provinces. In Quebec and Alberta, it is often available only in urban settings. There appears to be some form of parent counseling available to parents with resources and information to seek it out everywhere with the exception of the Territories and Manitoba.

Because people are part of a system of family members, the person with a communication disorder cannot be treated without attention to the entire family. Effective therapeutic time may be spent in altering the family dynamics and making the home environment more conducive to growth. A parent of a handicapped child (cited by Garguilo, 1985) hoped that each professional person would consider the family's needs along with those of the child for then, and only then, would their assistance be both practical and humane. Little direct family involvement has yet been addressed in most treatment programs (Luterman, 1984).

Counseling, as defined by Luterman (1984), is "an educative experience occurring between people, which is problem-centered and allows for the expression of feeling (affect), permitting and encouraging growth in both parties" (p. 2). When professionals become the 'ultimate rescuers' of the handicapped persons and their clients are kept from assuming responsibility for their own behavior, their growth is limited and they feel controlled and powerless. Counseling must encourage the clients to take responsibility for their responses to the events in their lives (Luterman, 1984). People may chose to grow from adversity and make it a positive experience or they may feel sorry for themselves (Luterman, 1984).

A team approach would be beneficial in diagnosis, planning and decision-making to afford parents the knowledge, understanding and attitude to proficiently exercise their responsibility as the primary decision makers, caregivers and teachers of their own children (Childhood Hearing Impairment, 1984; Griffith & Scott, 1985; Luterman, 1979; Mindel & Vernon, 1971). This team may include: child's parents; educators; audiologist;

social worker; trained parent volunteers; psychologist; professional family counselor; psychiatrist; and other medical service personnel such as an opthalmologist. Occupational therapists, physiotherapists, and speech-language pathologists may also be involved. General Practitioners, who are often the first professionals involved, must be better informed to prevent faulty or delayed diagnosis. Parents have needed effective coordination of existing services to decrease the confusion, to eliminate contradictory advice and information, and to access other needed professionals.

A wide range of information was needed by parents in a study of twenty pairs of parents, each pair with a normal newborn child (Kliman and Vukelich, 1985). They found that both parents lacked considerable knowledge about the normal growth and development of children and held inappropriate expectations for their child. Typically the parents believed their child's behavior would occur later than what was predicted by child development experts (Kliman & Vukelich, 1985). Parents also needed information on education, communication methods, audiological items, the deaf community, marriage, vocational planning, social and emotional development.

Professionals need to develop skills or to involve other colleagues to work with parents of adolescents (Blair, Wright, & Pollard, 1981). Parents often need a great deal of help when their children reach adolescence, "not only in managing the child but in managing their own feelings and anxieties" (Luterman, 1984, p. 148).

Counseling of Adolescents

Bonham, Armstrong, and Bonham (1981) studied the effectiveness of group psychotherapy with deaf adolescents. They found that this method provided effective prevention and early detection of emotional difficulties. In the group, adolescents could explore the group's potential for developing feelings of mutuality and concern for one another. This type of counseling was supported by various other research projects reviewed although there has been relatively little other research on counseling of hearing impaired adolescents. Bonham, Armstrong, and Bonham stated that the group discussed topics such as getting along with friends and family, adjusting to living with hearing loss, planning for the future, feeling isolated, assuming responsibility, dealing with frustration , expressing feelings,and improving communication skills. The healthy interaction that developed in the adolescent group carried over into the home and school environments (Bonham, Armstrong, & Bonham, 1981). Griffith and Scott (1985) and Murphy (1979) recommended genetic counseling for the adolescents irregardless of the etiology of their hearing loss.

Relationships of Parents and Professionals

Parents, cited in Sonnenschein (1984), have declared that, "whenever parents of handicapped children meet or talk together, a frequent topic of conversation is the perceived lack of empathy and understanding by 'professionals' of the parents' concerns, pressures and goals for their children" (p. 129). "Doctors and professionals give you textbook answers and truly believe it is the right advice. Yet none that I have met have lived, for even one day, with a child like mine" (Nastoff, 1986, p. 43). Numerous articles, books and statements by parents have described uncomfortable encounters, disappointing relationships and pervasive feelings of interactional difficulties with professionals. "Platitudes do not console, unrealistic advice does not help and misguided reassurances only worsen reality", (Fairchild, 1980, p. 1008).

The parent and the professionals may bring negative feelings and behaviors to their interactions which may interfere in establishing a good relationship. Limited training in parent education, professional insecurity and a competitive and nontrusting attitude toward the parents have limited good parent-professional programming (Bodner - Johnson, 1980).

Professionals must recognize the importance of keeping parents informed and working together to plan their future. "We parents need truth...let's be honest with each other and let's work together..[and]share the methods that are working", (Fairchild, 1890, pps. 1010,1011). A parent cited by Garguilo (1985) suggested that professionals could be of greater assistance if they would be more realistic and discard their ideas about stages; instead they should begin to understand something about the deep, lasting changes a handicapped child brings to parents.

Generally, professionals who have dealt with parents have been younger and not parents themselves, which could cause the professionals to have felt insecure and defensive. As long as the professional could lecture and tell parents what to do, the relationship was controlled by the professional (Luterman, 1984). Attention must be focussed upon the child but the parent, too, must be effectively involved.

"The psychological effect of sympathetic and effective management at the time of diagnosis and immediately after [was] crucial to the parents' realistic acceptance of their child's permanent hearing losses and their subsequent involvement in constructive training procedures with their children" (Williams and Darbyshire,1982, p. 25). Professionals must attempt to be nonjudgemental and honest regarding the limits of their own knowledge and abilities and take the concerns of parents seriously listening to the parents with openness, and compassion. Communication, respect and sensitivity are crucial. Information should be provided to the parents although they should be encouraged to ask what they need to know. Professionals should be knowledgeable of local parent and professional organizations, community resources and services (Garguilo, 1985; Luterman, 1979).

One recommendation by Bodner-Johnson (1980) was that the professionals learn to think of parents as individuals who have duties, jobs, hopes, bills, limited knowledge of deafness and responsibilities for other family members. Luterman (1984) stated, "I have learned, although at times it has been painful to my professional ego, to trust people to make their own decisions. I figure that they know what is best for themselves " (p. 103).

Education of Hearing Impaired Students

Education of hearing impaired children has a variety of instructional methodologies available and is an important area for consideration by parents, students and teachers. Parents decide, based upon availability of programs, whether the child should be placed in a day or residential setting, integrated or segregated program, using oral or a combined oral-manual communication method. Other considerations which require parental input are: support services such as a tutor or aide, the long and short term goals, the use of auditory equipment, the availability of programs, financial considerations and the needs of the family. These decisions may have been made in conflict with opinions and emotions of professionals and program philosophy.

There is an educational dichotomy concerning the use of the oral and the Total Communication methodologies in the teaching of hearing impaired students that dates back several centuries in history (Arnold, 1984). Proponents from each of these methodologies have attempted through research and practical examples to persuade others that their method is the appropriate method for education of hearing impaired students. "There is a great deal of controversy in deaf education. It seems that everyone has the blinders on for their particular bias, unfortunately, confused and hurting parents have to try to make sense of all the conflicting information. What we [his parents] are doing may not be right for all families but I feel very strongly that parents should be made aware of all the options available to them" (Kulakowski, 1984, p. 9).

There is a tremendous amount of literature that describes the advantages and disadvantages of the Total Communication, oral-aural, unisensory, and mainstream educational settings. Arnold (1984) suggested that researchers, professionals and parents have vested interests in the methodology and data they support. There are successful children in each of the programs but not all students nor parents can cope in all the programs. The family, child, child's hearing loss, and cognitive and social functioning, should be considered when choosing the child's educational placement but as yet there are no undisputed guidelines for choosing programs for these children. Placement decisions and the child's progress must be continually monitored and changes made if necessary. Parents need to be active participants in all parts of educational planning and decisions must be made on an individual and situational basis.

In a study by Bodner-Johnson (1985), parents felt that they had lost contact with the school when their children became older. They enjoyed the closer relationships with the school when their children were younger and expressed the need for renewal of information and involvement with the school and were eager to participate if the school were to initiate contact (Bodner- Johnson, 1985). Schoenwald-Oberbeck (1984) suggested a home/school partnership model to provide parent participation, education and counseling and to involve ideological commitment from the teachers, administrators and family .

Education is often geared to the needs of hearing adults and has, "long centered on the concept of continuing childhood and immediate desires of the parents" (Garretson, 1981, p. 15). Parents and educators overlooked the fact that the children would one day be adults. Garretson (1981) believed the experiences with deaf adults were important in the context of early education. Hearing impaired children must someday face the world as adults and parents would benefit from remembering that their children will someday face the responsibilities and requirements that life as a hearing impaired adult might entail.

The vast majority of professionals have felt that parents were important yet only half of the facilities surveyed by Cartwright and Russell in 1979 (cited by Luterman, 1984) had any organized program for parents. In many programs informal parent training has been at the supervisor's discretion. Bodner-Johnson (1980) described the professional preparation of education for parents which, on the whole, does not formalize training of professionals to work with parents in the teacher training curriculum; it is often left to chance. Many programs have concluded that parents are important in the development of the child but few have provided course work, training or practicums to effectively involve and train parents. Parent programs have often failed, a reflection of the failure at the training level to provide good models of parent programming. Many young professionals, such as teachers, speech pathologists, and audiologists, leave their training programs with minimal or inadequate experience in relating to parents (Luterman, 1984). Professionals to work with parents need to be chosen on the basis of their cognitive skills as well as their emotional maturity. More personal growth experiences for students should be built in at the training level.

Summary

The greatest impact of deafness is upon the family unit and the relationships of its members. The relationship between the parents and the child, which can be healthy or experience numerous problems, can have a signficant influence on the development and later acheivements of the deaf child. The discrepancies in the expectations of parents, the reality of the situation and the parents' reactions to their child's hearing loss pose a major hurdle in the parents ability to cope and adjust successfully. Several parents have published their experiences describing the events and emotions they have encountered because of their hearing impaired child. The research stages of parental adjustment, whether based on a time frame or emotional framework, do not necessarly capture the experience of those parents although they are useful to explain many of the actions, emotions and reactions of the parents. The siblings of hearing impaired children play an important role in the successful functioning of the family yet little attention has been paid to the emotional development of these children and their relationship with their hearing impaired sibling. Grandparents and other relatives or friends may also be a part of the process through which the family continues to thrive in spite of problems.

Hearing impaired children are generally believed to experience a variety of problems to a greater extent than do normal children although all adolescents tend to undergo the same physical maturation. There are discrepancies in the literature regarding the actual incidences and severity of the social, emotional, and behavioral functioning problems of hearing impaired children and youths but there remain few services and programs to alleviate the difficulties.

The speed of diagnosis, and method in which it and the parents are handled also may affect the effective development of the family and child. Parents are usually the first to suspect a hearing loss in their child whereas the doctors are apparently the least alert to possible hearing losses in a study of several various groups of professionals involved.

Communication that is two way and fluent is crucial to development of the individual. Negative social outcomes and hindered development may result due to early communication deprivation and lack of effective communicative exchanges.

Because of the effects of deafness, parents, siblings and the hearing impaired children require assistance in coping successfully with life's demands. Effective, impartial counseling would be of assistance to all members of the family. Support from other parents, professionals and family members can be beneficial to the coping skills and adjustment of parents and the development of the children.

The relationships of parents and professionals can have a great effect upon the participants but too often these interactions are disappointing and upsetting for the parents. Greater understanding and empathy by professionals could alleviate some of the estrangement of parents and professionals. Several methods exist for educating hearing impaired children but a variety of factors must be considered by parents, students, and professionals to decide which method is the most appropriate.

A number of areas have been studied to provide insights into the effects of hearing impairment and the development of the hearing impaired child. More research is necessary upon the meaning of this information to those affected by it. Thus, the present study has explored the meaning and context of the experiences of mothers of hearing impaired adolescents to contribute to filling this current gap in the research literature.

CHAPTER III

Qualitative Research Methodology

Currently, there have been two broad categories of research: quantitative, and qualitative. This study used a qualitative research approach drawing upon a psychological view of phenomenological research methodology.

The Necessity of Research

Research and the advances made through research have served a purpose in the lives of people. Educational research, somewhat like the process of education, seeks to reveal meanings of which individuals were previously unaware. Barritt, et al. (1983) explained that, "Research is not synonymous with statistics, research methods, writing articles or having a Ph.D. Rather to do research is to learn from experience, to cultivate a sense of wonder at what happens, to be amazed at the things...Researchers who ask honest intriguing questions have no right to expect anything more fulfilling than broader clearer understanding and better questions for the next go round " (p. 141). Research is a process through which greater understanding of humans and one's world may be gained.

Qualitative and Quantitative Approaches

The concepts of quantitative or qualitative research have not yet been settled, "even among those who have thought about them most deeply"

(Eisner,1981, p.5). The physicist P.W. Bridgeman stated, "There is no scientific method as such...The most vital feature of the science's procedures has been merely to do the utmost with the mind, no holds barred " (Bogdan & Biklen, 1982, p. 39). In order for science and research to be meaningful and of assistance, it must be able to respond differently to different circumstances. Natural scientists, who have used the quantitative research approach, have created and utilized methods that have depended upon the problem to be solved. As the study of humans and the qualitative research methodology continue to develop with an increasing number of researchers becoming involved, methods will become more readily defineable and distinct. Until that time, there will continue to be varied approaches within the phenomenological and qualitiative frameworks.

An example comparing both quantitative and qualitative research was taken from Barritt, et al. (1983). Water has been scientifically broken into its physical properties resulting in the description of water as H_2O. The experience of swimming and fishing in water is not lessened nor denied because of the representative symbol, H_2O; instead the scientific analysis and the experience of water exist as supplementary dimensions of what is water. Neither description is better, but the appropriateness of each depends upon one's purpose and situation. Qualitative research, in this example, the meaning of the water, and quantitative studies or water's physical properties, have become necessary forms of research with varied purposes that yield different information.

Quantitative methods may be used to discover what causes the relationship between two variables to be statistically related whereas qualitative research may explore the meaningful variations in the quantitative data (Bogdan & Biklen,1982; Fischer & Wertz, 1979; Polkinghorne, 1983).

According to Eisner (1981), the major distinction between qualitative and quantitative research is the mode of study, not the phenomena. The approach and method used have depended upon the question, aims and demands of the phenomena and the particular researcher. The approach has been permeated with decisions of how, and what aspect to study of the phenomena (Colaizzi, 1978; de Koning, 1979; Wertz, 1984). Fischer & Wertz (1979) stated that ideally the areas of research could include both forms of data each aiding the design of study for the other although distinct in their approaches.

Quantitative research has generally beenbased upon three propositions suggested by Descartes in the 17th century. These were the person/world split, humans viewed as mechanisms, and the body/mind split. In the first of these, organisms were viewed as reacting in predictable ways to stimuli in the environment. Only the objective world was seen as worthy of study because one used natural science techniques; the subjective world was not as readily examined and was therefore an unreliable data source. For the second proposition, mathematical methods for analysis of human behavior were often used and the only human behaviors that were deemed worthy of study were those observable, measurable, quantifiable and replicable under laboratory conditions. The last proposition, the body/mind split, involved the concept that humans were composed of two independently functioning separate components that could be studied separately: a physical body and the spirit/mind. Research in this view excluded both physical and aesthetic responses and was limited to intellectual responses of humans (Manasse, 1987).

Quantitative research has consisted of many straightforward requirements to which researchers adhere. There is a definable method which must be performed by many researchers and the characters and variables must be observed, measured and agreed upon by more than one observer. So-called subjective experiences have been viewed as beyond the scope of scientific investigation. Researchers have to: be dispassionate, objective participants; measure what they have studied; control experimental conditions; carry out procedures to ensure results apply generally; and be able to predict what will happen next time (Barritt, et al., 1983; Giorgi,1985; Wilson, 1982).

Qualitative research is more than precise responses to experimentally applied stimuli; it includes the world and the meaning one attaches to it. It does not attempt to describe correlational or causal relationships, although it can inform and supplement the information gained through correlational and experimental research. A majority of the studies in natural science research are experimental or quasi-experimental,, of a cross sectional and longitudinal focus. This type of research has provided a type of cause and effect imagery but attention has not necessarily been paid to the distinctions, contrasts, or actions among members of a culture. Reducing human phenomena to isolated variables then conducting experiments in a laboratory with them has eliminated the important context of the phenomena (Barritt et al., 1983; Nash & Nash, 1981; Polkinghorne, 1983; Wilson, 1982).

History

The history of a person, people or culture in quantitative studies has been controlled through the assumption that because of the impossibility of knowing everything, no relevant history is included . In many qualitative studies, the relevant aspects of the past have been allowed to present themselves both for the researcher and those whose experience is being explored. The training and experience of the researcher is also addressed through the process of bracketing in the qualitative approach. The past is important because of the role it plays in discovering the meaning of experience.

Instruments

The instruments used in quantitative research are formally predetermined as the primary basis for collecting data. Data are turned into certain kinds of numbers to attempt to generalize formally beyond themselves (Eisner, 1981).

In qualitative research, the researcher is the key instrument and the data is the lived experience of the participants. The researcher and the co-researcher enter into a relationship that is not as bound by time limits and standardized methods as in the quantitative field. The useful research tools of the researcher are the person's probings, observations and inferences. Qualitative researchers use their own personal reactions and intuitions in regard to the event and the person's report to create a refined account of the experience of the people (Barritt, et al., 1983; Giorgi, 1985; Wilson, 1982).

Objectivity

Objectivity has been possible in quantitative studies because the collective subjective experience of people has been so trustworthy. A red light, an ambulance or a smile are understood to have similar meanings by most people who share the same culture although each situation changes the perceptions so that these are not understood in exactly the same way. Humans live in an intersubjective world and if people could not trust the subjective experiences of everyday life, then the interpretations of ordinary events would become unreliable and idiosyncratic. There must be some reliance on subjectively constituted experience of the researcher, participants and the members of the culture in general (Barritt, et al., 1983; Salner, 1986).

Social practices of groups of humans are not reducible to the individual's experience yet, in mainstream social science, these common meanings between people generally find no place. These meanings have a place of their own because collectively they are created over time and transcend the individual's ability to shape them (Salner, 1986). Humans achieve intersubjective agreements that are held by a culture or group of people; therefore experience is communicable and not ultimately subjective.

Piaget, cited by Salner (1986), stated that objectivity meant, "he who tries to avoid the illusions of his self in studying methodologically the reactions of others" (p. 128). Objectivity may be best served when the contributions of the researcher are acknowledged to the form of the findings and others are encouraged to approximate the researcher's perspective to see for themselves what appeared (Fischer and Wertz, 1979). In this way it is known that any discipline's knowledge is inevitably based on perspectives of the researchers whether utilizing quantitative or qualitative research.

Quantiative research attempts to make knowledge 'subject-free' or 'objective' by extracting the researcher from the experience. This has often provided sterile, artificial categories for the knowledge base (Polkinghorne, 1983). In so-called "objective" studies, there is a loss of information because personal insights of researcher and co-researcher are replaced by constraints on procedures and reporting, and idiosyncrasies are not included.

Because of the involvement of humans and their experience, objectivity cannot be attained and it is impossible for researchers to rid themselves of personal bias. Questions, questionnaires, and experimental studies reflect the interests of those who construct them. Research is conducted personally and represents the researcher's beliefs in areas such as the importance of the person, the value of the procedure, the significance of the results and the method of presentation (Barritt, et al., 1983; Bogdan & Biklen, 1982).

In a precisely controlled objective study in which the examiner has a high degree of involvement with the subject during the treatment, the meaning of the results is harder to interpret than for an observation session of an ongoing event. "It is impossible for meaningful human science to be anything but subjective...given the nature of the subject, there is no alternative to subjectivity" (Barritt, et al., 1983). Both the observer and the co-researcher are part of an interactional system in which they are defined in relation to each other. The presence of a researcher, called the observer effect (Bogdan & Biklen, 1982), changes the behavior of those involved as the researcher's behavior itself takes upon methodological dimensions. The researcher intrudes into the co-researcher's world making interpretations within some kind of conceptual scheme. The method to least distort the person's experiences is an attempt to understand the co-researchers from their own point of view (Bogdan & Biklen, 1982). Qualitative researchers attempt to interact with the co-researchers in a natural unobtrusive nonthreatening manner that is not as artificial as when studied in a laboratory. The more controlled and obtrusive the situation, the less likely the effect of the methods and treatement are being studied. The goal of pure observation free from theoretical, social, historical or cultural bias is not realistic.

Validity

Validity, in quantitative research, is the extent to which the tools measure what they were intended to measure and to which the results could be accurately interpreted and generalized to the general population. The assumption exists that experimentation ensures that the data gathering tools are reliable and standard to make replication possible and to produce a correspondence between the tools being used and the external reality (Salner, 1986).

Qualitative research has different aims and measures for validity. Nash and Nash (1981) stated validity for qualitative studies included the judgement of: how well it preserved the participants' standpoint; whether systematic distinctions and meanings that were recognizable among members of a culture were generated; whether it informed the outsider of the insider's perspective; and whether it described explicitly the method by which the ends were said to have been achieved. Two researchers studying the same setting could gather and produce different data yet both studies are replicable. The training and questions the researcher bring to the study affects their inquiry (Bogdan & Biklen, 1982). "Defensible knowledge claims", as termed by Salner (1986), are more suited to qualitative research.

Generalizability

Generalizability, in quantitative research, refers to whether findings hold up beyond the specific research subjects and the setting involved. This is an attempt to derive universal statements of general social processes, not commonalities of settings, although that may be done. Other studies might have been drawn on to establish representativeness (Bogdan & Biklen, 1982). Well defined methods of generalizing have been used in the quantitative research methodology through randomly selecting the sample and setting universal parameters with inferences from the sample to the population acceptable as they meet these requirements (Eisner, 1981). The researchers seek trends, central tendencies or stable and statistically significant differences in the variances between groups as a function of treatment. Researchers are only interested in the particulars as they represent the general. Studies of single cases or of idiosyncrasies have not been considered adequate for generalizing because 'outlyers' or individual scores that do not conform to the distribution are often disregarded and considered part of the error variance. The interests are with the population, not the sample itself.

Barritt, et al. (1983) stated, "The more general a statement, the less likely it will apply to the individual in front of you now " (p. 37). Sole reliance upon general characteristics have caused individual differences to be overlooked. The outlyers, although discarded in quantitative research, add depth to the qualitative exploration of experience. If human events were idiosyncratic or varied with time, place and cultural circumstances, and if rules of probability didn't apply to people as they did to seeds, for example, then generalizability could not be reached (Barritt, et al., 1983). Averages, whether means, standard deviations or variances are statistical artifacts and do not adequately describe the members of any group. Barritt, et al. (1983) stated there are more important aims than achieving generality; these are to be relevant, honest, accurate and useful.

The qualitative method, according to Eisner (1981), does not have a comparable mechanism for generalization as in the quantitative approach. The general is believed to reside in the particular and what one learns from a particular situation might apply to other situations encountered. Humans are shaped by what is learned from individual cases and the ability to generalize from particulars is one of the ways people cope with the world. Qualitative research attempts to illustrate significant common human attributes through writing about particular individuals. A sense of recognition in individuals who have had similar experiences can be evoked typically with meaningful description. This type of research seeks to ascertain the applicability of an interpretation to other people's experience of the same phenomena. For example, Shakespeare's Lady Macbeth was not just one English woman in a castle but was an example of common traits of humanity. The general is to be located in the particular of qualitative methodology.

Theory

All research, according to Bogdan & Biklen (1982), whether stated or not, is guided by some theoretical orientation. This theoretical orientation or perspective is a way of looking at the world with assumptions about what is important and what makes the world function. Theory helps data to cohere and enables the research to go beyond aimless, unsystematic piling up of accounts. Good researchers are aware of their theoretical base and use it to collect and analyse data (Bogdan & Biklen, 1982).

Phenomenological Research Approach

The purpose of the phenomenological method, according to Giorgi (1985), is to do justice to the lived aspects of human phenomena which requires first knowing how people actually experienced what they lived. The essential purpose of phenomenological research is to discover the meaning of, and not how to measure, the phenomena (Giorgi, 1971).

To do phenomenological research is, according to Barritt, et.al, (1983), similar to arriving during the middle of a movie when one needs to ask, "What is this story about?", "Where does it begin?", and, "What are the significant or insignificant parts?".

"A consensual, univocal interpretation of phenomenology is hard to find" (Giorgi, 1985, p. 24). Phenomenology has not been sufficiently institutionalized in the same sense as have other research approaches such as behaviorism. There are few precedents with little overlap from previous problems that might be drawn on during the research process. Giorgi (1985) stated, "An acceptable, generally agreed upon manner of conceptualizing phenomenological psychology and conducting phenomenological psychological research, so that psychologists wanting to theorize along the same lines or to perform research know precisely what to do or when to use as a model, simply is not available " (p. 52).

Phenomenology is the science of phenomena or experience and enquiry into everyday natural experience, not contrived experimental settings. Researchers attempt to describe what is given to them in immediate experience when their preconceptions and theoretical notions are put aside for the moment, or bracketed. Phenomenology is prompted by open-ended questions of experience of the situation with the subjects, called co-researchers, who are unfamiliar with the researcher's theories or biases. The protocols, whether an interview transcription, written materials, or fieldnotes, are used to find meanings, patterns, themes and explanations. Phenomenological researchers attempt to discover, account for and understand the meaning of events that have used descriptive, interpretive and critical devices. The goal of this approach is to understand the co-researchers from their own points of view with awareness and appreciation of the other's situation. Accurate perspectives of the participant are important with the researcher checking out these perspectives with the co-researchers. Description and meaning are central to this method (Bogdan & Biklen, 1982; Colaizzi, 1978).

Phenomenological studies have been written in the first person which assists in conveying the personal flavour. The practice of writing in the first person has been advocated in phenomenological research to render accounts as vivid as possible and to convey that all experience is potentially common experience and therefore to be shared (Manen, cited in Manasse, 1987). Barritt, et al. (1983) explained that, "Rather than recognition and acceptance of the power of an individual's thoughts, we have a ruse to escape them...[we don't] use 'I' but use the researcher as more neutral" (p. 44). The first person style of writing will be used in the section of the bracketing by this researcher.

Remembered Experience

Phenomenologists have stated that what people remember they have a motive for remembering (Manasse, 1987). The past, as it appeared to the person at that moment, may be the most significant for that person because relevant experiences are meaningful. Memories are an essential part of every experience because from memories of our prior experience, come our ability to act, to think, and to talk about what is happening. "Recollections are themselves interpretations of the event and what has come after" (Barritt, et al., 1983, p. 142). Without memories, every experience would be new and humans would be unable to even talk about them. It is impossible to separate memory from experience (Barritt, et al., 1983). Memory and the experience of time are locked together. Remembered experiences are part of our lived experience and therefore an area suitable for study (Van den Berg, cited in Manasse, 1987). Barritt, et al. (1983) stated that:

> recollections [for them] of past experience were a legitimate, and sometimes the only source of information about important events. We believe that these recollections should be used with the acknowledgement that they were not exactly the same as the original experience but that they nevertheless speak significantly about that experience...If the researcher places recollections in the context of the informant's present situation both can be better understood. Collecting material from several sources can further help to bracket the present from the past ...understanding the immediate experience was enhanced by including different recollections and that was a completing [of and] not destroying understanding (p. 142).

Structures of Phenomenology

The ultimate findings of phenomenological research are presented as essences or structures. "The structure of the phenomenology is defined as the commonality running through the many diverse appearances of the phenomena" (Valle and King, 1978, p. 16). Structure descriptions are the most invariant comprehensive meaning, are not universal nor eternal, are grounded in the data of experience and are the result of a careful viewing freed, as far as possible, from suppositions. Structures or essences are the basic unchanging nature of the phenomena revealed through meaning. The ultimate goal of phenomena is to uncover the structure of the phenomena under study (Manasse, 1987).

Participants in Phenomenological Research

The informants in this type of research have been called co-researchers. Co-researchers are viewed as life world experts in the phenomena. They may take the role of describer; describer and co-interpreter; or co-author of the final conclusions (Becker, 1986).

Becker (1986) stated the main criterion in selecting subjects is whether the researcher judges that the research goals could be accomplished using the data obtained from a given number of co-researchers. One basic qualification of participants is possession of salient experience of the phenomena in their everyday worlds. It is preferable that they be centrally involved with, and have had many life experiences of the phenomena. The researcher had to bear in mind that all participants disclose their experience to a greater and lesser degree with a variety of salience(Becker, 1986).

Another qualification for co-researchers is their articulateness, which is the fluency and ease with which people express their experience. Co-researchers have to be willing to struggle verbally with describing their everyday experiences of a particular phenomena. They must be open to their own experience and be willing to share their experience with the researcher without intellectualizing about the material. There are no 'right' responses, therefore the co-researchers may freely express the fullness of their remembered and imagined events and the variations that have occurred (Becker, 1986; Colaizzi,1978; Polkinghorne, 1983).

Choices for participants could include: the researcher; one other person; a diversity of people such as those of different ages, socio-economic level , gender, and religion. Level of involvement and demographic information may also be used as part of the criteria. The number of co-researchers depend upon the factors to be examined which may include: the quality of the interview data, and the researcher's sense of how well the view of the essential aspects of the phenomena has been provided; the availability of co-researchers; the audience the research is directed to; what kind of insights into the phenomena the researcher wishes to highlight; and how wide a view of the phenomena the research wants to portray (Becker, 1986; Colaizzi, 1978)

Contrasts among groups of co-researchers or diverse single subjects help to illuminate structures and the constituents of the phenomena. The researcher uses the number of co-researchers necessary to manifest the variations of the whole phenomena and to achieve the aimed at generality. The diversity of these participants must be considered regarding the phenomena in light of the interest and choices that have to be made. As wide as possible a variety of examples and co-researchers could be studied through the phenomenological research methodology (Becker, 1986; Polkinghorne, 1983; Wertz, 1984).

The Interview

Interviews through which the researcher and participants may converse and dialogue freely may be used to conduct a phenomenological study. The interview is an encounter which may proceed in its own way if handled properly and is a good method of collecting the lived experiences of the co-researchers . Many authors have utilized this method (Aanstoos,1986; Barritt et al., 1983; Becker, 1982; Bogdan & Biklen, 1982; Giorgi, 1985).

The model interview is relational and dynamic similar to two trusting partners conversing, not formally asking and answering questions in a researcher/respondent exchange. The meaning and the object of experience are between and not within persons. To fully explore a concept it requires understanding of how a concept operates among people to create a meaningfully shared encounter with experiences (Becker, 1986; Bogdan & Biklen, 1982; Polkinghorne, 1981; Strausser, cited by Polkinghorne, 1983). The interviewer and interviewee attempt to capture the participant's lived experience which lay outside of the interview. The interview process provides a human context that allows the co-researchers to articulate their complex, lived experience. This immediate personal contact enables the participants to receive immediate responses thereby increasing the likelihood of authenticity. The interview approximates everyday discourse which allows the dialogue to move back and forth in time to recount experiences (Becker, 1986; Manasse, 1987; Polkinghorne, 1981).

The type of interview chosen depends upon the goal of the research. Different types of interviews may be employed at different stages of the same study. At the beginning of a project, a more free flowing type of exploratory interview can be used to gain a general understanding of the person and of the topic. After the investigatory work has been completed, the interviews may become more structured to obtain comparable data across a larger sample or to focus on particular topics that have emerged during the first interviews (Bogdan & Biklen, 1982).

The most important principle of the interview is respect for the interpersonal encounter between the people involved. The interviewer has to attempt to possess empathy, care, authenticity, sensitivity, responsiveness, playfulness, flexibility, openness, and curiosity. The researcher must be present with, and participate in the shared life world of, the other person. Mutual trust and respect needs to be established to enhance this process and there should be no judgement of the co-researcher by the researcher. If the interviewer is personable, skillful and lucky, he or she may enter the life world of the co-researcher (Becker, 1986; Polkinghorne, 1983).

During the actual interview, the purpose of the interview and its unstructured format is explained to the participants. This assists the co-researchers in understanding that what is valuable is their description of their experience (Becker, 1986). Wertz (1984) suggested that by precisely specifying the interests and procedures of this research approach, mutual understanding in reference to the phenomena itself is possible. Being completely open about the research question and the goals helps to equalize the power imbalance inherent in research and invites the interviewee to be co-researcher (Becker, 1986).

Initially the co-researchers should be encouraged to feel comfortable while describing their experience (Aanstoos, 1986). The participants are asked to describe their experiences of the phenomena in everyday living as if they were re-living them, then an attempt to made to elicit more detailed description of the situation (Becker, 1986). The interviewer continues to interact in a nonleading manner following the structure of the participant's description and asking for elaborations and examples in ways to encourage the person to struggle with wording of their lived experience.

Laferriere (cited in Becker, 1986) suggested three interview contacts with the participants. The first contact is called the structuring interview and involves orienting the participants to the research project and to the nature and intent of the interview. The rights of nonparticipation, confidentiality, informed consent and guarding the person from harm through the interview process were discussed. The second interview involves the gathering of the data and the third one is the corroborative interview. In the latter meeting, the researchers check their understanding of the data and test the limits of the previously elaborated upon descriptions. Polkinghorne (1983) suggested that the researchers could return to the interviewee to seek more full detailed description for information explored at the first interview.

How and when to end the interviews, according to Becker (1986), is an intuitive evaluation by the researchers. If the researchers could produce substantial insights into the phenomena from the analysis of the data and the researchers felt that they knew the co-researcher's view from the inside, termination of the meetings could occur. If the themes were repeated and the general trends anticipated, the interview process could end (Becker, 1986). There is no prescribed length of each interview or number of interviews, according to Polkinghorne (1983).

Bracketing

Bracketing is a crucial part of phenomenological study (Barritt, et al., 1983; Becker, 1986; Bogdan & Biklen, 1982; Polkinghorne, 1983). The reader of the study is able to know before beginning what are the researcher's major interests, questions and commitments and why the researcher is doing that particular study in that way. Barritt, et al. (1983) believed it was important to state clearly the feelings, beliefs and commitments before, during and after the interviews. They stated that, "Human investigators are like a magnifying glass...they focus on something and bring it to light. Readers [of the study]..see something in a new way with some distortion. Telling about yourself, making yourself a part of the study, allows the reader to know where distortions could lie. The result was a clearer picture which was the best we can hope for" (p. 133).

Qualitative research, of which phenomenology is one approach, attempts to acknowledge, take into account, and deal with the preconceptions and biases of the researchers. Polkinghorne (1983) stated, "we must cleanse ourselves of presuppositions, those expectations of what he/she will see" (p. 7). Researchers must also be aware of emotional and other personal factors. Qualitative researchers attempt to guard against their own biases by bracketing their presuppositions. Becker (1986) stated that the researchers must carefully interrogate their own presuppositions and bring their implicit knowledge of the phenomenon to their explicit level of awareness. This sensitizes them to the difficulties the participants may have in articulating their experience. Once the researchers are aware of the presuppositions, they are more able to put them aside and less likely to impose them upon the co-researchers. This process could also alert the interviewers to possible themes that might require clarification if alluded to by the co-researchers.

Bracketing is an ongoing process as researchers learn to confront more of their presuppositions. Personal integrity and awareness of one's own biases are required and researchers continue to check their biases by returning to the experiences themselves. The bracketing process places stringent demands on the researchers to question their own work. Researchers have to use self reflection over time and use bracketing to test new themes as they emerged in the interview and in previous descriptions (Polkinghorne, 1983).

Before and after the interviews and data collection, researchers spend time becoming aware of their assumptions, expectations, presuppositions and biases. This could be done by writing, talking to a friend and/or tape recording them (Becker, 1986; Polkinghorne, 1983). A research journal could be used to record the thoughts, experiences and reactions of the researchers throughout the research process.

Most phenomenological researchers, other than perhaps Husserl, do not believe that a pure presuppositionless point is attainable (Polkinghorne, 1983). People cannot rise above the historical and cultural circumstances of their lives nor could the suppositions that are inherent in existence as humans be entirely overcome. The features of personal gain, prestige, social recognition, moral, ethical, religious, political and economics factors can not be eliminated (Colaizzi, 1978). Researchers must determine why they are involved in the research, their personal inclination and predispositions regarding the research, their values, influences or biases.

Data Elicitation and Type

In quantitative research, data are gathered before being analysed. In phenomenology, however, the themes and ingredients generated by the data are incorporated into the next stages of data gathering and used in part to test one's initial suggestions. The collection and analysis of data are two processes that interact with each other throughout the study as the researcher continues to uncover the meaning of the experience (Polkinghorne,1983).

Altering the design of study during the course of an investigation is not unusual in phenomenological research (Wilson, 1982). Since it is characterized by an emerging and not a prefixed design, the study is expected to evolve as it progresses hence changes occur.

Descriptive data in a qualitative approach may be elicited in several ways which include: questionnaires with open-ended and specific questions; interviews based on the questionnaires; spontaneous dialogue, or group discussion; collaborative statement of both researcher and participant(s); reports of nonverbal behavior or physiological movements; and journals. Description that is already available in scientific tests, literary, biographical, and philosophical works could also be used (Wertz, 1984). Written information, dialogal interviews or observation may elicit descriptive data (Colaizzi, 198). Special purpose logs, or journals, although not as revealing as diaries, provide hints of what life has been like for the co-researchers. These are usually written under the influence of a experience and could be effective in capturing the person's thoughts and moods (Bogdan & Biklen, 1982). Other sources of description for phenomenological study are: one's own remembered and imagined description; portrayals derived from interviews or written statements given by others to participate; and depictions of the concept or operations by prior phenomenological researchers, novelists or poets (Polkinghorne,1983) . Visualizations may be used to develop rich descriptions, and imagination, remembrance, thinking, and hallucination may be utilized in this research (Polkinghorne, 1983). The researcher during the interview may take additional notes regarding the co-researchers' nonverbal gestures and cues to supplement the audiotaped interview (Bogdan & Biklen, 1982; Polkinghorne, 1983).

The actual raw data of phenomenological research consists of descriptions of actually lived through experience. The focus is on the phenomena, "specifically understanding as that which appears, exactly as it appears to one to whom it appears" (Aanstoos, 1986, p. 10). Uncovering meaning depends upon the bracketing of the naturalistic prejudices and presuppositions to shift focus from the preconceived concepts to lived meaning (Aanstoos, 1986).

Summary

In summary, this chapter of the research methodology discussed the importance of research and its necessity in the lives of people. Quantitative and qualitative research were compared and contrasted on dimensions such as inclusion of history of the participants, research instruments, objectivity, validity, and generalizability. An explanation of qualitative research focussing upon the phenomenological approach was presented. Also discussed in this chapter was the procedure for interviewing, some suggestions for interviewing techniques and the roles of the interviewer, the researcher and the interviewees, the co-researchers. Ongoing bracketing by the researcher is crucial to this research approach thus the philosophy of bracketing and methods to bracket was included. Although data elicitation and the process for reaching the meaning of the experience are entwined in this research, the method used by the researcher to uncover the meaning of the co-researchers, in this case the mothers, will be discussed in the next chapter.

CHAPTER IV

Methods and Procedures

Statement of the Problem

In this research project the co-researchers were asked the general question, "What was your experience as a mother of a hearing impaired child?". The interview was initiated by the statement to the effect of, " it is your decision as to what parts you want to disclose, in what depth and where you want to begin."

Equipment

The equipment used for the audio-taped interviews consisted of lapel microphones worn by the researcher and the co-researcher hooked into a cassette tape recorder; the external microphones of the recorder were also used. The tapes were a maximum of sixty minutes although the pilot interview with the first mother was ninety minutes. A simple coil notebook served each mother as her journal. The researcher also kept a journal to assist in bracketing her presuppositions and biases, and to make notes prior to, and after, each interview session.

Research Procedure

For the present project, initial contact with each mother of a hearing impaired adolescents was made through a telephone call to explain the reason for and the methodology of this study. The interview schedule, their time commitment, and their responsibilities should they agree to participate were also explained. Confidentiality was assured. During this initial contact, a meeting time and place was arranged for the first interview.

Due to the very real fears of the mothers and because confidentiality is essential to this type of research, the names of the participants, the places and the programs that were mentioned have been changed. The sexes of one, some or all of the children have also been altered to further prevent the parents, and thus the children, from being identified in this project. Some of the experiences have been slightly modified to ensure confidentiality which does not, however, alter the flavour or the meaning of the lived experiences. The means of communication utilized and the educational programs the children are enrolled in have not been altered; the communication mode and type of educational program provide crucial background information to their experiences.

The first interview was a sixty minute audio-taped session. Time before and after the taping was allowed for formalities, and for further explanation of the concepts. During the first interview, each mother completed a Demographic Data Sheet (Appendix A) and signed the Consent Form (Appendix B). After these formalities, the nature of this project and their involvement in it was explained in detail. The first session with the mothers lasted from a minimum of one and one half to a maximum time of two and a half hours. The researcher met three mothers in their own homes, one at her work setting and one at the university. For all but one mother, the setting of the second meeting was the same as the first.

During the two to three week interval between the two interviews, each mother was asked to keep a journal of the thoughts, feelings or incidents which occurred during that period about their experience as mothers of hearing impaired children. All but one of the women completed some portion of the journal component. Pam did not write in a journal explaining that, " I talk better than I write". The journals varied in length from several to many pages.

The second meeting took place from three to three and a half weeks later and lasted from one and one half hours to three and three quarter hours. Three purposes were addressed in this session which included: inquiring what the mother had to add; answering questions pulled from the original protocol; and discussing the themes that had emerged. The mothers were also encouraged to add, emphasize, and delete comments throughout the session. For the most part, the mothers agreed with the major themes that were pulled from the interview transcripts; they elaborated to some extent upon the experiences related from the first interview and changed some of the researcher's wording of phrases. To faciliate an informal, comfortable setting for the second interview, the interview was not audio-taped but handwritten notes were taken to record the information.

Participants in Study

Five women, all of whom are hearing, participated in this study. Deaf mothers of deaf children were not included in this study because a fluent, shared communication system was not present between the researcher and participants which would hinder the nature of this research. A professor at the university acted as an intermediary in initially approaching four of the mothers who participated in this study with whom she had had some prior contact. The researcher had had previous contact with one mother through becoming a support person to her child, and with two other mothers who had been met briefly the year before. The participants have been described as they were at the time of this study.

The women are caucasian females from 38 to 49 years of age. Two of them are married, and three divorced. Of those three, two are living as single parents. Each of the women has two or more children, the most being four. Their level of education ranges from completing grade 12 to post-graduate study. Four of the mothers have taken college courses and all have been enrolled in some post secondary training. Regarding their current working status, one mother is on welfare, two mothers do not work for pay outside of the home and the other two mothers are employed in fields unrelated to deafness. In general, four of the women are in the middle income level and one is in a lower income level.

A brief summary of the working status and communication methodology of each of the mothers and their children follows. Diana is working fulltime while her son, Ken, attends a class that utilizes total communication. They use sign language, speech and audition to communicate. Pam and her daughter, Paula, utilize the oral method when communicating. Pam is on social assistance and Paula no longer lives with her mother. Joan is a homemaker who communicates orally with her daughter, Sheila. Carol, a homemaker, uses audition and lipreading to communicate with her daughter, Erin. Leah and her daughter, Donna, use sign language and lipreading to communicate and Leah works fulltime to support herself.

The range of the children's ages is from twelve to eighteen years. Four of the children had a pre-lingual hearing loss and one child became deafened at the age of two and a half years old after exposure to language. All but one of the children experience profound hearing losses in their better ear; the other child has a severe hearing loss.

Each child's educational placement is different at this time. Three children are following an oral route with varying amounts of additional educational support and are all in integrated educational settings. Of this group, one child has few supports, one child has a tutor and part time support, and one is seen regularly by a variety of specialists. The other two children use a total communication approach in a special and a regular academic setting. Three children utilize lipreading, speech and audition; one child utilizes sign language and lipreading; and one child utilizes speech, sign language, lipreading and audition.

The involvement of the mothers in parent groups varies. Over their hearing impaired child's lifetime, the participation of each of the mothers has varied from none to a great deal of commitment. To some degree, all the involved mothers have moved away from their participation in the field of deafness and two mothers have removed themselves completely from deafness-related groups.

Treatment of the Data

The purpose of the treatment of data is to uncover the constituent parts and their relationships. The process, not just the product, is important. Similarities are not merely compiled but a deeper level of description of the essential elements is striven for. Every statement is examined due to the assumption that nothing is trivial but that each statement has the potential for being a clue to unlock more comprehensive understanding of the phenomena (Bogdan & Biklen, 1982; Polkinghorne, 1983). The direction is gained after the data is collected because the picture takes shape as the parts are collected and examined. Researchers do not fit together the pieces of a puzzle that were already known; instead the picture emerges (Bogdan & Biklen, 1982).

Treatment of the data for this project was accomplished through a series of steps based upon work by Becker (1982), Colaizzi (1978), Giorgi (1975, 1985) and Polkinghorne (1983).

The first step for the researcher was to skim the protocol, or taped interview transcript to acquire a sense of the data and to understand the co-researcher's language, then it was read in more detail. Descriptions, or transcribed interviews, could require more than one reading to acquire this.

The protocol, which was still in the co-researcher's language, was re-read slowly delineating each time a transition in meaning occurred in the second step. When the researcher became aware of a change in meaning of the situation for the co-researchers, this was noted directly on the description. A series of meaning units (MU), or constituents written in the words of the researcher, were created by breaking the protocol into solitary statements . Each part of the meaning unit that described one aspect of the experience was written out. The MU exist in relation to the attitude and set of the researcher depending upon the researcher's perspective. For each MU in the co-researcher's language, the researcher produced a more direct MU to discern its meaning.

The third step was taken to eliminate redundancies, clarify, and elaborate to one's self the meaning of the units by relating them to each other and to the sense of the whole. The researcher organized the meaning units along thematic lines, then into clusters of themes. The selection of the themes to be used to organize the MU was the creative task of the researcher. These were checked by referring the theme clusters back to the original. Everyday language was used because, according to Giorgi (1985), there has not been an established consensual psychological language.

After thematizing, the researcher, in the next step, identified the essential elements of the concept. A specific theme might be based upon the experiences of only one participant. The more examples available, however, the greater the variations and therefore an increased ability to see what is essential. All transformed MU were taken into account.

The researcher returned to the protocol to use imaginative variation to test the fullness and accuracy of the structural description. The descriptive statements differed in their level of description. The technique of imaginative variation allowed the researcher to test various ingredients in the samples of remembered or imagined experiences providing a variation in the strength of the different ingredients. A continuum of the experiences that remain examples of the same phenomena may be gained.

The researcher then synthesized and integrated the insights into a consistent description of the structure of the phenomenon. Ideally each descriptive statement comprehends a large set of facts and deepen the understanding of the phenomenon. The structure was communicated to colleagues for confirmation or criticism. It is important to return to the examples to discern if the structure is present in each of them. Various examples of a given experience were needed for comparison to identify the essentials of the experience from what was particular to only one example (Polkinghorne, 1983).

The final step included returning to the co-researchers to inquire whether the findings were applicable to each of them. The new data that emerged from this session was then worked into the final project.

In this study, a pilot project was initially undertaken by the researcher for a research methodology course. One mother was interviewed two times and the first interview lasted approximately two hours, in which the nature of the study, her responsibilities, and a second meeting time several weeks later were discussed. During the ninety minute taped portion of this meeting, she described her experiences of being a mother of a hearing impaired child. Between the first and second interviews with this mother, the researcher read and re-read the interview transcript to begin the treatment of the data. Each change in meaning in the words of the mother was noted on the protocol; these demarcations are called meaning units. The researcher then reworded the mother's meaning units into the researcher's language. For example, a statement from one of the mother's transcripts was, "I'm just about ready to take her out of the program". The meaning unit was written as, 'The mother was contemplating removing her child from the school program'. The researcher's meaning units were then placed in meaning clusters, then grouped into major themes.

The researcher returned to the interview transcripts to list the mother's actual words under each appropriate theme. The themes were ordered from most to least salient. During perusal of the transcripts, several questions for the participant to answer in the second interview were formed from the first interview regarding information that was puzzling, needed elaboration, or lead to other areas of discussion.

The piloted second session with the mother was not audiotaped but the researcher took handwritten notes. As the themes were discussed, the mother added several new experiences, emphasized or modified the wording of some of the theme statements, and answered the researcher's questions. The mother agreed with the researcher's ordering of the themes from the first interview.

With the themes from the interview transcripts and the additional information from the second interview, the project was written up and evaluated.

For the other four mothers, the process for the interviews and the steps taken by the researcher were similar. The main difference between the interview with the mother for the pilot project and the other four women was that during the second interview themes that had emerged for the other women were discussed in addition to the themes and questions from that individual's first interview transcripts. For example, the second mother to be interviewed was questioned about themes that had emerged from an interview with the first woman but which had not appeared in the second mother's taped transcripts. There was no one else from whom to cross check themes for the first woman interviewed therefore this step could not be included in the pilot study but was included with the four other women.

Between the first and second interviews, all but one of the mothers kept a journal of varying length of some of her present and past experiences with her hearing impaired child. The information in these journals was included although for the most part there was little difference in the experiences related during the time with the researcher and the material in the journals.

Once all of the second interviews had been completed and the information collected, the researcher synthesized and integrated the insights into a consistent description of the structure of the phenomena from all of the mothers. Themes common to the mothers were described and handled by the researcher. This process required repeatedly sifting through the themes from each of the mothers and then examining them across all of the experiences of the mothers.

During this treatment of the data, the researcher kept a journal to be used to bracket her reactions, emotions and thoughts throughout the research process. The bracketing of some of the researcher's most salient biases, opinions and reactions is described in the next section.

Bracketing by the Researcher

The ongoing nature of bracketing is a process through which researchers attempt to guard against their own biases by becoming aware of and attempting to put aside their assumptions, expectations and presuppositions. This process assists researchers to be more open-minded and alert to the co-researchers' difficulties in articulating their experiences. Through explicitly stated bracketed information, the reader of the study can more readily adopt the researcher's viewpoint and more clearly understand the research results. Bracketing is a crucial component of phenomenological study (Barritt, et al, 1983; Becker, 1986; Bogdan & Biklen, 1982; Polkinghorne, 1983). The researcher has described her bracketing in the first person as suggested by Barritt, et al. (1983) and Manasse (1987).

My area of interest and recent training is in the education of hearing impaired children although I have not yet taught that population. I am young, newly married, and childless. At this time, I do not hold vested interests within the field of deafness nor do I only advocate a certain methodology, or particular school of thought. Through my undergraduate work and masters program, there has been little, if any , time spent upon the theoretical and practical implications of the role parents play in the development of their children's personal and educational well-being. Several of my teaching colleagues in regular classrooms have stressed the importance of parents in the school, yet they have not been adequately trained to effectively deal with and utilize parents in their school plans. Parents need to be active participants in all parts of planning and decision-making and educators need to be formally trained to more effectively facilitate this process.

I have attempted to make explicit my presuppositions throughout this research process. Prior to the first interviews, I wrote my presuppositions in my research journal and after each interview, working through each protocol, and meeting the co-researchers for the second session, I continued to write them down or to discuss them with another person. The pilot project conducted with one mother was a beneficial learning experience because I received feedback regarding my procedure and tentative conclusions, and was able to review and refine my interview technique treatment of the data. The following are some of the presuppositions I have attempted to bracket to more fully understand the phenomena of the lived experiences of women who are mothers of hearing impaired children.

Between the first and second interviews with one of the mothers I found myself feeling condescending toward her. I felt that she had been misguided, had chosen wrongly and her story was "untrue", and I looked for ulterior motives at her attempts "to cover up" what was in fact the 'truth' of her situation. I was "smug" feeling that I, as a trained professional, would have made better choices for her child and family although I later realized that the choices they made were appropriate for their situation.

The first interview with this same mother may have also been affected by a variety of conditions that altered her descriptions, my questions and our interaction. While reading and treating the transcript from her interview, I strongly felt this negative attitude and continued to find examples to confirm my perceptions. Prior to my second interview with her and because I had been dreading this interview, I presented some of my findings to another person with the rationale that if I could discuss the findings and my feelings with somebody else I would feel better being involved in the interview. During this bracketing process, suddenly it hit me that I had assumed the position of the "all knowing professional" who had all the right theoretical answers; I had missed the experience of this person. It was not my place to judge whether her experience was real or right to me because the important and valuable part was her experience. With this new perception, I had a much more open and accepting attitude in the second interview with this mother and thoroughly enjoyed our discussion.

The importance of bracketing was illustrated for me because without this second interview accompanied by bracketing of my opinions and impressions, I would have had a totally different perspective of this woman and her life. I labeled her as, "denying ...not facing facts", in my research journal yet after our second interview my perception of her was changed. If I had met with this participant only once, I would have interpreted her experience according to my first impressions missing an opportunity to understand her experiences from her point of view. Regarding the second interview, I wrote, "It was a whole new world that opened up for me."

The day prior to my interview with the aforementioned mother, I interviewed another mother who made a comment that remained with me, "It's just two groups [of parents], the ones who deny everything is all right and the ones who can spit it out and say it's never going to feel alright." The woman the next day stressed how well things in her life had gone and my reaction was to believe that she was denying her experience. Once I was aware of that perception carried over from a previous conversation, I was able to more readily examine her experience on its own.

The process of bracketing and becoming aware of my reactions to others was a tremendous learning experience. It was very easy to assume the "hat" of a professional which seemed to distance me from the person to person interaction in the interview context and to be affected by the thoughts of one person in my interactions with someone else. Judgement of another person's experience often happens without taking into account the situation, the person and the decisions made leading to that place in time. People, whatever their vocation, must become increasingly aware of their perspectives because these perceptions affect the interpretations, the decisions and the treatment of those involved. Person to person, not 'professional' to 'unprofessional', it is easier to work together to find solutions. Perhaps then, fewer individuals will "fall through the cracks" of the system and more will be facilitated to reach their potential.

The second interviews with the co-researchers were not audio-taped. The complete recording on tape of information was outweighed by the possible inhibitory factor of the taperecorder; I wanted interaction to be as comfortable and fluid as possible. With one mother, I found a difference in our interaction between the taped and non-taped interviews. In the first session, there were many pauses and stammers, whereas the second untaped interview was filled with easy interaction and an abundance of lengthy anecdotes. Other factors to affect the interview process, besides the possible effect of the taperecorder, may have been my uneasy feeling at being taped, my questions, or that we knew each other a little better in the second session. This specific session was the only meeting in which the researcher and co-researcher sat opposite each other across the table; this may also have affected the flow of the interview.

After completing the first interviews with the mothers, I felt discouraged at being a professional person. The mothers shared with me many more unpleasant, than pleasant, experiences they had had with professionals. At one point, I was angry at professionals in general, believing them to be insensitive, rigid, and nonfacilitating, and I began to feel badly that I was to join their ranks. I realized, gradually, that many of these unpleasant experiences were more salient and easily remembered by the mothers and upon further questioning in the second sessions, all of the mothers described pleasant and helpful interactions with professional people. I had easily adopted the critical perspective expressed by these women towards the professionals but once I had placed this information into perspective, I was able to examine all sides of the issue and became encouraged to be a professional.

As a human researcher, I experienced varied reactions to the experiences the mothers related to me. When mothers described their pain and feelings of burden and frustration because of their hearing impaired chilldren, I initially felt that this was an abnormal reaction. Upon examination of that preconception recognizing that even mothers with normal functioning children sometimes feel the same way, I was able to better understand their experience. The pain, sadness, bitterness and frustration in some parts of their lives also disturbed me. We must attempt to respond honestly to these stories as revealed through the person to person interaction.

I have a tremendous amount of respect for these mothers and am somewhat in awe of their life experiences. For the most part, they have dealt with their respective situations quite well and have overcome many of their problems; I admire these women.

CHAPTER V

Results of the Study

Themes

Each of the themes that have emerged from this study is presented in this section. A summary of the main components of each theme is included with illustrations in each mother's own words of salient experiences they have related. The confidential nature of this type of research prevents full transcripts for each mother being submitted in an appendix. Rather, a sample of each mother's words and/or description of her experiences by the researcher are presented to demonstrate the themes, and provide a richness of illustrations in text.

Theme I - Personal Development

The most dominant theme culled from the research was the personal growth over time of the mothers initiated by having, raising and interacting with their deaf children. The traumatic life event of a hearing impaired child offered the mothers a chance for growth that was, at various times, rapid, slight, great or blocked.

Growth occurred for these women in ways such as taking decision-making power, embarking on a career, and taking a variety of roles as mother, teacher, supporter to her children, and parental advocate. With so called "normal"children, it is an added bonus for parents to become involved in their children's lives in areas such as the educational and communication process but with hearing impaired children their involvement is a necessity.

Three women emphasized the impact of their child's deafness on them. Leah stated that her personal growth was similar to, "peeling an onion, you know like, this won't do, this won't do, oh, this is what it is!" Her daughter's deafness was her, "external motivator because my own inner growth wasn't enough." Ken's mother, Diana, described the consequences of deafness of her child as, "It changed me entirely...I couldn't have asked for a better experience...I look back and see how I've changed and the person I was to what I'm now, I'm pretty good, I've learned a lot, grown...I was stretched emotionally, physically, spiritually and intellectually beyond my limits...I didn't ask for it...it's a lot of hard work." Joan summarized her reaction as, " Having a hearing impaired child, I expect any other kind of handicapped child, you grow very, very much more than I think if you had...normal kids." Of the other two women, Carol explained that her awareness and perception of life has increased in a multitude of other areas. Perhaps because of other problems in addition to deafness in Pam's family, the hearing loss of her child did not seem to have as great an effect upon Pam. Not one of the three divorced women attributed her child's deafness as the sole cause of her marital breakup.

The suddenness and intensity of the debilitating effects of deafness can catapult mothers and fathers into a situation filled with unknowns. The parents are left to cope as best they can, choosing doctors, programs, teachers, even a communication method with which to attempt to understand and be understood by their child. This situation can foster personal growth for the women in several areas.

Roles of the Mother

These women have taken a variety of roles such as interpreter, supporter and teacher in their interactions with their hearing impaired children. The mothers have also advocated on behalf of their children with a hearing loss. Diana neatly summed up this perspective by, "I really didn't think when I became a mother that I was supposed to be a warrior, you know, I kind of thought nurture and not battle!"

Support

Support by mothers of their children is expected in most societies and with the intensified relationships of mothers and hearing impaired children, this support tends to be more long lasting and encompassing. The mothers may become guidance person, advisor, counselor, or best friend for their children. Each woman supported her child in a variety of ways and degrees.

Carol Carol and the family were Erin's major support network until Erin's first year of high school at which time several peers developed into close friends and support for Erin. Prior to that time, Carol stated her great deal of support and role of sounding board for Erin definitely assisted her daughter to cope in her life. Carol became Erin's "outlet" at lunch and after school which allowed Erin to share her stories immediately after events had occurred. Together, they would then make plans with the teacher, principal or by themselves.

Erin had few friends at school and was experiencing difficulties with some of her peers. "The one thing that was important with this whole period of being harassed [by students at school], I think the important thing that kept her sort of on top of it was that I was here, she'd come home at noon or after school with these stories and she'd be upset and then she'd tell it, all right then you know, five minutes later it's O.K. But I think if she didn't have somebody at home at that period I don't know what would have happened. She'd have probably kept all that in...I think of my role with her is mostly support whenever she comes with whatever, you know, and already I don't think she needs me so much, but she did in the past for sure just to come and say it all and that's it."

Erin has developed some close friends in the past few years but Carol explained Erin's aloneness by, "some of us are loners, I like it. I come to the group for something but I like going my own way." Carol talked at length about the friendships of her daughter. Up until recently Erin had no friends, "and that was our big worry, well the whole junior high she didn't have a friend, so she was alone in the junior high , the only deaf kid with no friends...that was the worst part of junior high, not the school or the teachers or the work or the deafness but the lack of a friend...also the part, you know in junior high, you have your certain bullies well she was taunted and teased and bugged and so those two things caused her junior high to be quite hard...well there was a lot of trauma with that part of her life...now that she is in high school she has at last made friends...[they're] interested in the same things and they get along just fine. She did have a hearing friend that was only in the city for a short time but they have been writing, corresponding over the years...she did see her last summer and they've maintained their contact and partly because of their shared interests." Problem solving together and with others and the availability of an empathetic source in Carol enabled Erin to more effectively deal with and be free of her problems until Erin developed other friendships and support sources.

Leah "[Donna] tells me alot of things - she feels better and I feel ahhh!!! and think... her mental health is in jeopardy ." Leah worries and "gnashes" over Donna's feelings of being ostracized and rejected one day, and then the next day she says she feels good about herself except for her deafness. Leah encouraged Donna over the years to be involved in a variety of activities, and would also attempt to answer her enquires as best she could.

Joan A minor theme, stated Joan, was that she and her husband helped Sheila to find her way. "It was Sheila who took the initiative in most ways..sometimes misguided and quite definite on things she wanted and wants to do...[she can be] really exasperating sometimes because of this independence."

Diana Diana supported her son and her friends supported both of them.

Pam Pam was discussing her child and that,"she has all the special attention a kid could need now...at this point in time right now, she's got a pretty good support system right now...how long it's gonna last I don't know...[they may give up on her] which they probably will end up doing but I hope not." Pam has supported her daughter in that she had attempted to access services on her behalf.

Teacher

Mothers of handicapped children are often expected to fill the role of teacher and of parent. Some parents, such as Diana, felt that the assumption of such a role is abnormal, although she herself assumed the role at one point. Joan, and to some extent Carol, did not explain this function as normal or abnormal, but as being necessary. Becoming a teacher of a child, no matter the age, can become a full time job along with other life tasks and the other roles of support person, interpreter and advocate. For most of these mothers, the "teacher" role took precedent at times over their other responsibilities.

The involvement of the mothers as teachers varied from woman to woman. The description of their participation follows.

Carol Carol said she did regular home therapy with Erin when she was younger although as Erin grew older, homework became the main 'teaching' function which was accepted by all of the family members at different time periods.

When Erin was young, "No one else could do it, so I did it. It became a regular routine especially when she was young. Now that she is older it is hard to do speech therapy with her but now she asks if we are correcting all of her errors." In the early programs she gave her time fully, "I took it on myself to get it done. The other family members would sometimes get involved. One person worked well so I took the responsibility...It wasn't really that much, it was a certain portion of the day and it wasn't very long." They took turns in the family doing homework with Erin although one of Erin's sisters was more "adept and patient than the rest of us."

Diana "Becoming a teacher for your child I think that's abnormal, I think its vital parents understand but if you become a teacher...then you lose out on your ability to be maternal...I was caught up in language input and deafness, I was caught in either the teacher or the advocate role and isolated from my mother role...It's like make mother the instant expert and isolate father or vice versa." Mothers often experience difficulty juggling their respective functions in the family unit.

Joan Joan discussed the rationale for choosing to be at home with Sheila," there was an awful lot to be done at home... I think it's paid off in the long run...and our minds function very much alike, it's scarey sometimes I can see her heading down the wrong path and you hate to see your children pick up your bad habits... and I think that period of time when we worked together so hard even though she didn't know she was working hard was the time we really formed a strong relationship which has stood us in good stead...and, she is fun to have around ... We just didn't have that early help available from anybody else and I'm not sure that anyone else could have done it, the handwriting was on the wall, somebody had to stay at home and do whatever could be done at that point" . When Sheila was young, Joan worked a tremendous amount with Sheila. She disliked house work and baking but these became important daily lessons with her deaf daughter. Sewing, something else she was not fond of, became a challenge as mother and child worked together on it. Initially Joan did not know much about children and deafness, but,"logic said this was a child who happened to be deaf so we had to look at all aspects of it."

Leah During Donna's early years of education, Leah was an important component of the programs. When Donna entered the school system, Leah decided to assist Donna with the community aspect such as softball, guides,and coping strategies for these areas, and left the academic portion to the school. Leah's role was more of a guide than a teacher of academic topics in this sense.

Pam It is unclear from available information whether Pam did a great amount of teaching with Paula when Paula was young. Once Paula had been diagnosed as hearing impaired they had little, if any, intervention from the professionals. Pam stated, "I figured well, this kid's gonna be deaf and I better do something, there's got to be something I can do anyway." She mentioned watching a show where they taught children and parents about the vibrations of sound and putting your hands on cheeks and lips of the speaker and attempted to implement what she saw with her daughter. She does not now assist Paula with her academic studies.

Advocate

Another area through which mothers may experience personal development is that of advocacy. As advocates, mothers strive to gain services, programs and funding while attempting to maintain workable interpersonal relationships with those involved. Most of them spoke of fighting for services for their child. "Walking on eggs" was how Joan described this process.

Of the five women interviewed, Carol was the only mother who stated she did not have to fight for services for her child because she had been satisfied with the services received and the professionals involved. Carol and her husband were, however, active in a city parent group that acted in an advocacy capacity.

Each of the women viewed this struggle for services in various ways. Diana was feeling worn out but was coming in for the "second round", Joan was upset at the waste of time and energy it had been, Pam stated she was frustrated and oppressed by it all, whereas Leah and Carol were not as involved or concerned by the issue.

The age of the child seemed to affect the mother's perceptions of this fight. Diana, whose child was the youngest in the study group, seemed to be the most integrally involved, whereas Leah, whose child was the oldest, seemed to be most removed from it. Perhaps parents of elementary and early junior high age children are most active in the advocacy role and once their children are somewhat settled in or are finished with the system, this advocacy role becomes less pressing for the mother.

An interesting consideration is the mothers view of people who fight for services or being viewed in this role. Neither Leah nor Carol described themselves or others in reference to this struggle. The other mothers described people who fight the system, or themselves in that role, as follows: Pam said, " [you're considered a] troublemaker, you're emotionally disturbed or you need a shrink because you can't handle the problems...or you may be classed as a radical"; Joan has heard herself described as a "rampaging woman"; and Diana stated that people, in trying to acquire services, "sometimes rebel, and start you know, putting emotional bombs in people's systems, or you pull back." Feelings and events related to this advocate role are described by each mother as follows:

Carol Carol did not view herself as fighting for services. She and her family followed the advice of professionals doing the best they could within that setup. She decided not to interfere with the school, "I didn't want to start any kind of problems...I didn't know whether I should go there and start fighting her battles at the school or what...we had conferences at the school about [the bullies] and we, all the teachers and us agreed that it wasn't worth coming down on these kids about it 'cause they were like that to everybody."

Leah When Donna was a young child, Leah decided against the will of the professionals she was dealing with to move Donna into a Total Communications program. After they moved when Donna was older, Leah stated, "there were no options" because only one appropriate placement existed for Donna, that of a Total Communication setting, in which she was then enrolled. She was able to access adequate services for her child.

Pam Pam stated, "It's been a fight since the day she was born. Hopefully with enough fighting and what not, screaming and yelling they'll help her...I've had lots of fights with society, bureaucracy, whatever you want to call it...that's the way it's been going for years, you got to put up with those things when you're dealing with government officials or the bureaucratic system."

Pam also encountered financial difficulties. Not one of the other four parents discussed the cost of raising their children, except when specifically answering the researcher's question regarding their children's educational funding. Pam stated, "when you have a handicapped child , you're begging for everything and basically in my case anyway and I know it's the same in a lot of cases they don't have the income to pay for all the things yourself so you've got to depend on the government which you don't want to do but you've got to, you've got no choice, to supply the hearing aids."

Pam stressed that when pushed sufficiently in a situation, she would act to help her child; getting angry was often a prerequisite for Pam to obtain services. She stated she did not get angry often, "like it takes a lot to get me mad because I've only been mad a couple of times in my life but you don't cross me 'cause I get done what I have to get done because I really don't care how it happens...That's what I have to do, I have to get mad, I have to start cursing and swearing before anybody listens." She described one incident in which she went "up one side and down the other" of her child's principal. "When I left there [the principal] understood what I was talking about and a few changes were made."

Diana Diana explained, in our first meeting, her feelings about her repeated attempts to receive adequate services for her hearing impaired son:

> Most mothers in this age group have fought and fought and fought and they're tired, and either they're coming in for their second round, they've been burned out for three or four years and they are going to make another kick at it or they're burned out... it's a big stress. I am so burned out fighting for decent services for that child that I take what I can and I'm willing to put up with a teacher I would not allow near my other

> children because I'm just too tired to fight anymore...it's become very difficult for me to mobilize myself and make change in that situation and I know how much time it's going to take me.

At the beginning of the first session Diana was rhetorically asking, "what am I doing, and why isn't there something as good for this kid when he has so much potential, why am I in a situation where I can't give him what he wants?...How can I as a parent be allowing that teacher to continue with my child day in and day out insulting her like that? And what does that say about me as a parent? That's what's really my primary struggle is how can I allow that to go on?"

Towards the end of that same interview, her statements changed to a more optimistic, action oriented vein. Examples include,"you know, whether I say I am burnt out, tired, or not, it's just not a good enough excuse, because it's encouraging...and I wonder about abdicating my authority and if I am so committed and so worried about these philosphical things I need not abdicate that authority and allow things like that to go in the school...I have been describing the last six months to you and so I am feeling kind of inspired about putting some markers into play..."

The interaction of parent and teacher is important as is their balance of power. Diana discussed a strategy for learning to cope effectively with a teacher with whom a parent does not agree. "What do you do in a situation like that [when a teacher inappropriately punishes a child], do you witness for that kid or make a fuss or when do you stay silent?...so it's how to support these teachers to work through some of their junk I guess...how do we help to get them to a more people centered place rather than just use my instincts and throwing them out...how can I practise so that next time this happens I can at least clear my throat you know little baby steps, you know, it's hard...but somehow putting a marker in that says right now that's not O.K....and I know what Ihave to learn in all this, and I guess what you struggle with too, is how to be pro-active in these situations, how to give the teacher that feedback that at least from me I didn't like what you just did, so easy to talk about and so hard to do."

Diana was having some difficulties with her child's teacher and was feeling that the principal as well would not be open to her input. She contacted the principal of her son's school after our first session and discovered that communication between the teacher and herself had been bungled. The principal sorted out Diana's concerns still leaving the benefit of doubt to the teacher. The teacher after Diana's phone call to the school seemed to be more positive and accepting of Diana and her child.

Joan "We had to be so careful not to antagonize people because they're the ones working with her, we had to convince them [the professionals] that they should try something and so sometimes, most of the time, we felt we were walking on eggs, it gets to be very stressful after awhile", explained Joan.

Joan and her husband decided they had to be very well informed although many parents do not have adequate information and are therefore very vulnerable. Before Sheila had reached elementary school, Joan had had lots of exposure to the field of deafness and had a start on the educational aspects. "My way of dealing with problems is to learn what I can do about it."

Joan and her husband took an active advocacy role. Both of them were very involved with the school board and she with several agencies. They were part of a parent group which lobbied for funds and programs, distributed information and was available for support of other parents. Joan discovered that, "a lot of parents don't either have the energy, the know how or the will to be involved..I mean [single parents] have got all they can do just to survive...A number of parents feel they can't rock the boat at all...I guess I could understand that but you just don't sort of sit there and take garbage...in later years we knew that it wasn't for Sheila anymore because we could see that her way was fairly clear, it was for the other children." Joan and her husband and the whole group in general are not as active in the group now at this point. Sheila's parents have started to distance themselves somewhat from the groups, which Joan described as a nice change. There is less of an emotional involvement for them now that Sheila is older. "Nobody can do anything about it[her schooling], a lot of the pressure is off when Sheila is at this stage, at the younger ages we did not know if the story goes on...I suppose you do these things because you think you have to do it to live with yourself, it's just one of these things."

In one meeting, Joan said the school personnel told her the reasons why they could not place her daughter where Joan had requested. Joan stated,"at that point it was as if they pushed a button in me and I said, 'I'm sorry I 've listened to your problems for four years now and it's time you listened to my problem.' " Her husband agreed with her requests and within one week her daughter was in the desired placement.

In later years, "because we were so adamant, [the school in spite of pressure from others] said we'll go with the parents on this and it's up to the child now...forceful parents get done what they want, they know the ropes...one lady I know said she'd call the minister's office." Sometimes they were heeded by those providing the services.

Joan resented the time demanded of her to fight for services and to deal with professionals. "Ninety percent of it shouldn't have happened, it is hard to figure out and accept." According to Joan, she and her husband were regarded by professionals as notorious parents. Joan countered that as parents they were reacting to others and to the situation, not just making waves. "Why were there such problems, other parents of deaf kids didn't undergo the same kind of hassles." Joan stated that some other parents did have similar if not worse experiences but the majority did not.

Joan and her husband did not discuss the problems they encountered gaining services or organizing professionals with Sheila. "In all our difficulties we didn't want her to be aware of all the things going on in the background. She didn't know about all the phone calls gone to the school."

Joan said they felt frustration and burnout regarding funding and allocation of monies marked for disabled children, "its very frustrating when you think the money is being misused or it's not being used in the most efficient way ." They kept records which fill two thick files on their involvement and correspondence with those involved. Joan thought they might give the files to the trustees who blissfully advocate how parents should be involved. According to Joan, involvement as a parent is a difficult task but one in which parents must persevere.

Interpreter

The mothers took the role of interpreter not only in the sense of relaying the message from speech to sign or lipreading, but also of interpreting the meanings of the child's surroundings and world. Leah stated,"it was a relief to have someone else interpret in the family group...[I felt it was my] moral imperative to interpret everything that was happening." She was her daughter's, "interpreter of the world, I mean interpreting what things are happening and why this and explaining how the world works, or trying to, and whatever she brought to me then I was willing to talk about it." It was not until Donna was much older that Leah began to give up that role and allow her daughter greater responsibility for that task.

Joan still has to act as a go-between on the phone with Sheila's friends and Joan said that hearing impaired adolescents, her daughter at least, share their lives a lot with their parents more so than do regular teens. Sheila can't use the telephone and therefore one of her family must act as interpreter for Sheila's calls. When a boy phoned Sheila, Joan told him that she would give her daughter the message; he didn't leave his name and Joan suggested they need to purchase a TDD, a teletype telephone that can be used by deaf persons to allow them privacy. Because Sheila and her parents get along so well it has caused them few problems in this area.

Pam often makes appointments and calls for Paula by telephone. Diana and Carol stated in their interviews that they have had to assist their children in learning about the world in ways other than the more typical ways.

Decision-Making Power

Whatever their respective situations, each woman experienced increased decision-making ability to varying degrees. Pam had long shouldered the responsibility of decision-making. She stressed that with her ex-husband, "I paid the bills, I took the kids to the doctor, I've always done that." Joan explained she had been a decision-maker all of her life sharing many of the decisions with her spouse. Carol, also made choices with her spouse and both she and her family connected with professionals and programs who tended to suit their needs; her's was a more limited decision-making role. Leah and Diana became the prime decision makers as head of their single parent family units. "An important experience for me", said Leah, "was to take back my power for decision-making and knowing what was best for my child, not giving up my power to all these various and sundry other people pulling me this way and that." As single parents with a hearing impaired child, Leah, Diana and Pam had to learn quickly to make decisions for the benefit of their children and themselves.

For some of these women, decision-making helped them to gain self confidence, self esteem, and assertiveness in all aspects of their lives as well, the process of making decisions and taking responsibility for the consequences is also fraught with anxiety. Several of the mothers stated their choices for their children occasionally were contrary to the "expert" advice of professionals; this often made decisions very difficult to make.

Career

The careers of the mothers, which are described as a chosen pursuit, work with or without pay that is in or out of the home, were affected in various ways by their children's deafness (that is, volunteer work can also be included in this definition). Two mothers entered new jobs, one mother left the work force to care for her child, one mother who had remained home with her first non-hearing impaired child became involved in various volunteer activities, and the fifth mother's status did not change. The two women who entered the work force began in deafness related areas but as their children aged, both mothers moved to non-deafness related occupations.

All the mothers, except Pam, have been involved in some type of volunteer agencies and boards that have been generally linked to hearing impairment although Diana stated that she volunteers with groups unrelated to hearing loss. These four women, especially when their children were younger, participated in a wide variety of activities. Now as their children are in early to late adolescence, they are less involved with groups related to deafness.

Each woman expressed a different reaction to her voluntary or forced choice of occupation. Leah and Diana entered the workplace which has become an area of satisfaction for both of them. Carol had chosen to become a homemaker for all of her children prior to the diagnosis of deafness in this child. Pam had a variety of jobs, been intermittently on welfare, and has completed training for an area in which she has yet to gain employment. Joan was the only one who expressed experiencing difficulty with her decision to remain at home with her hearing impaired daughter.

Joan Once Sheila was diagnosed as hearing impaired the stresses of the diagnosis of deafness, her husband being transferred and her own involvement in work were too great, thus, Joan left her career.

From the time she was young, Joan stated she was not, "a small child person," nor did she want to be a 'stay at home person'. She enjoyed work that had a high degree of involvement and that greatly utilized her mind. She said she could have coped with these factors individually but not all together. Joan said the first year, after Sheila's diagnosis of hearing loss, was an especially difficult adjustment although she has since enjoyed their time together and learned to adjust and pursue her own interests as well. She took a pottery class which was, "a therapeutic outlet and marvelous experience", and has become involved in several other hobbies. Involvement in Guides was a good outlet," a great way to meet new people if you have just moved from elsewhere" , and good experience.

Joan also became very involved in volunteer work, working on several boards with deaf education and her other areas of interest. She has been very selective with her time, becoming involved in activities that required personal input and planning on her part.

Now that her daughter is older she and her husband have not had to be so involved. They are not as involved in the parent groups although they are still somewhat involved in the parent support network.

Carol Carol has been involved in parent groups in the city for a number of years and in activities with her Church. She has been actively planning many of the meetings and social gatherings for the groups in which she has been involved. Her involvement level has, however, decreased slightly over the years. She has not been professionally involved in a deafness related field; this has, therefore, not changed. She chose to stay home with her children, working hard with her daughter, Erin.

Pam Pam has not seemingly benefited professionally from her child's deafness. She has not been permanently employed having been on welfare as a single mother although she has had several jobs over the years. She has undergone retraining for another occupation but that has not lead to a full or part time job at this time. Pam has not had any involvement in any organizations related to deafness, thus the impact of deafness on the advancement of Pam's career has been minimal.

Leah Leah's career was greatly affected by her deafened daughter. The statement, "in some ways...being the mother of Donna has really directed my life," focuses the effect deafness had on her career. She stated, " I've got to find out how to get through to this kid...and that's what drew me to the area which became my career...In a very real way, Donna was the initiator of that, or not Donna herself but my interest in education catapulted me into that whole area of work and studying."

Leah became involved in the area of deafness for a number of years working on several boards, and organizations relating to hearing impairment.

As Donna was finishing her years of school, Leah stated she found herself beginning to move away from the education of deaf students. As she stated, "there's definitely some parallel about her getting educated and me educating other deaf kids, and then when I feel as if she's educated there is no longer that need for me to be involved in education." When Donna was sixteen, Leah left the city to pursue further education in a field unrelated to deafness. She is no longer involved in groups that focus upon deafness-related areas.

Diana Diana stated deafness has," entirely shaped my career." She described herself as a, "housewife with no education..no expertise...and Ken and his communication handicap and volunteer work led me to going back to school."

Diana worked for groups in and out of the city associated with deafness, involved in various volunteer work and committees. When Ken was small Diana stated she was doing over 60 hours a week volunteering and another 25 hours per week as a board member for another group. Diana said in reference to her early years of volunteer work that she was very involved, "a professional volunteer." There was little time remaining for her children, her husband or herself. She spent time volunteering that as she stated, "I could have been in the sunshine or playing with Ken."

Diana also has turned away from the field of deafness putting more effort into the family and her other interests:

> I have severed every tie with organizations specific for the hearing impaired. I do volunteer work but when I do, I do it for other causes. It's a very deliberate move on my part. I feel that if I give back in a way that feels good for me, other people will give back in a way that feels good for them and it will benefit the deaf community...[the field of

> deafness] takes more of my energy I think than it would for someone who's distant, I've lived with deafness therefore doing volunteer work is just too much so I have withdrawn [from this field]...I have deliberately pulled out of working as a professional in the area of hearing loss because I am not effective and I have too much emotion and other stuff still.. but I am a lot stronger in other areas.

Theme II - Relationship with Child

The birth and raising of a child is an important component of life for many women. Between mother and child, strong emotions and bonds may form and with a hearing impaired child, these relationships of mother and child are intensified; this composes the second theme.

This theme is composed of three subthemes including: child as an individual; emotional content of mother with regards to child; and the separating issue of mother and child. Most of the mothers spent considerable time during the interview sessions discussing their child, generally in very favorable terms, presented in more detail within the first sub-theme, the child as an individual. Frustration, long term recurring pain, and a sense of being burdened were some of the emotions expressed by the mothers in relation to their hearing impaired children. The second sub-theme composed of the emotional content of the mothers presents some of their strongly expressed feelings. The last sub-theme involves the learning of independent behavior by the child. In much of the literature, the hearing impaired children have been described as being more dependent upon their mothers, or parents or others than would be expected for normal children (Lane, 1978; Marks & Cohen, 1978). Although this issue was an important theme for the mothers, all of the women explored this topic in the interviews and have made provisions for their children to learn independent behavior. The sub-themes involving the relationship of mother and child follows with the child as an individual presented first.

Child as an Individual

The mothers are fond of, and generally think highly of their hearing impaired children. Their perceptions of their relationships and of their children are presented for this first sub theme.

Leah Donna is, according to her mother, "a very strong personality..... a very powerful and strong kind of gal who verges on being rude... but who does have some redeeming qualities....Ms. Determination. " Leah agreed when the researcher suggested she felt awe for her daughter and her daughter's many accomplishments. When questioned if it was at her insistence that Donna worked hard, Leah replied that she did not overtly or consciously encourage her daughter but was interested in what she was doing. Donna is largely self taught and spends hours and hours on her work. Leah explained, "She went above and beyond [what the school taught] by just reading and reading and reading and asking questions."

Leah also stated that there was a "dark side" to her enthusiasm. So much of Donna's energy is put into her other interests that Leah is worried about her mental health and socialization in the larger world beyond home and school. "She's a kind of a loner, a reclusive type person and so that kind of concerns me you know, some of her socialization...and yet there are only so many hours in the day, she's devoted herself really to studying, reading and writing...I mean it sounds odd [because of the hearing impairment often English reading and writing skills are below par] but it's totally self motivated."

Leah stated that, "she lives better with it than I do......she has her own way of dressing and 'mother' panics ... it's my fantasy that she have numerous friends and have the time of her life at school - but in looking back at my life my parents didn't understand me and maybe that's how she feels about it.... I've got to learn to give her life back to her." Leah thought of herself at Donna's age as 'unique' and very individualistic which helped her to deal with what she termed, " Donna's differentness. "

Leah said Donna is difficult to live with, is critical and blaming. It seems that she feels Donna does not appreciate her nor is aware of the time, effort, and struggle she has had because of her. Leah said "It's hard to do what I've done - She's still wounded and needs help." She received a letter from Donna just before I arrived for our second meeting. She chuckled as she read it, but frowned as well. Leah was worried that Donna wouldn't make the necessary changes for her return home, and Donna was worried her mother would be late to pick her up. Leah exclaims, "My critical kid - and I react to that." Her background as a professional tells her to be calm, " but my back goes up" and as a mother she's mad. Theirs is a caring relationship yet each one calls the other stubborn and strongminded. The struggles are painful but Leah stated, "I like her. "

Joan Discussed her daughter,Joan stated, "I think she's phenomenal...she's just really very capable...I feel quite comfortable about her as she steps off into adult life, it's a nice thing to see and to feel...She's very persistent I guess if she doesn't understand something she asks, or if something's not going right she'll talk to them ...I'm just thankful that she being the kind of child she is she just didn't lose interest entirely." Sheila has a good sense of humor and can tell a good story in the way that is very funny and a real asset," especially with a group she knows." Her sense of humor and the ability to distance herself from the situation are coping mechanism according to Joan. Sheila is very self-motivated and determined which Joan described as, "having a child who intended to do whatever she was going to do regardless of what people thought...quite often we were running to keep up with her."

Sheila's experiences, although not all pleasant, have been benefical to her. Joan stated that Sheila learned to stand up to people and to walk away from certain situations. "A lot of the problems Sheila's had have made her more perceptive or aware of other people's difficulties." Her child has handled many situations which helps give her confidence in her child. For example, when she was eight a man tried to pick her up in a car and she didn't tell her mother until after dinner because Sheila didn't want to worry her mother. "Sometimes I think she's a little too cool about some of these episodes."

Joan said that Sheila feels that she is, " a person first and is deaf secondly ...she gets very annoyed when people put the deafness first and I guess this has been an ongoing theme...in a three page autobiography she did for school the last paragraph or so identifed her as deaf...so she's never really seen her deafness as a barrier..that has not been her problem. She's still battling some stereotypes, I guess she's felt really put down a lot over the years on different things...she felt last year that she could finally prove herself as an individual and she did and she really kind of enjoyed it... that they have accepted her and she felt she was being treated as a person."

In school, Sheila would sometimes eat alone at lunch or not join in with the other students. She would, in essence, "shut down" for a short while. Teachers and other students would sometimes misunderstand this, becoming annoyed with Sheila or wondering what was wrong with her. As Joan explained, they were not aware of the effort she had to expend in class and she needed that time to recover and refuel her energy. She is a very fast and efficient worker and sometimes people ,"take for granted what she can and can't do...she is a 'victim of her own successes...I don't know how she does it and the real difficulty in what she does...she makes it so easy, we even forget at home and sometimes she doesn't know what's going on...it's hard to realize there are limitations especially in discussions."

Sheila functioned very well academically and Joan stressed that, "Sheila set those standards... I guess a lot of them [the other children] have language difficulties which Sheila didn't have." Joan reflected upon the first interview that the emphasis had been on her daughter's academic performance. She had spent much of the first interview discussing experiences related to academics and associated problems but because of this emphasis she wanted to maintain a balance in the interviews. Sheila's family members, "don't look at Sheila as a [certain type of] student...school doesn't alter our view of the person...the whole emphasis should not be academic...it's not the important thing... it's been so important and problematic and therefore the situation where so much of the time [has been spent] ...it's taken for granted that that's the way it is..it's been such a big deal." Her academic performance is a bonus not a key point. Joan stressed that they regard Sheila as a person with a developed personality and interests who functions at various levels in different areas.

Pam Pam's daughter, Paula, has been experiencing many difficulties at this time of her life. "Now she's not just hearing impaired but she's going through several different worlds all in one, the fact that she's hearing impaired also the fact that she's a teenager and the fact [there are other problems] so that [she is in] these different worlds, each one is bad enough for a kid to cope with but roll them all in together you have problems. I mean she is a good kid, she is a very good kid, she has a lot of problems."

Pam and Paula have patterns of behaving with each other that cause one or both to become upset. Because of multiple family problems, Paula moved out of the home into another living arrangement.

Diana Although she is working full time this year, Diana stated that, "the other thing I'm working on is my relationship with Ken...a good thing came of our separation [Diana and her husband] is that Ken and I got close...I value that he and I have a relationship that works for us...I want the quality of my mothering to be there and I'm trying to put my energy there instead of into the concepts or the cause or the education."

Diana described her child as delightful, strongwilled and a social creature. She stated her son is, "intuitive, empathetic, with everyone and can find the emotional content in a session...he's a teacher for me in that way...he's got such skill and warmth." Ken is learning how not to be with people from some of his teachers and he needs others to sign with.

Diana's child has had struggles in school. He needs help in his reading and needs to develop study skills. She is worried about Ken's skills and his varied performance levels in school. Diana feels he has this "gauntlet to run" of high school and possibly post secondary institutions. Her child has also experienced trouble with the teachers in some of his classes.

Ken's relationship with his father has developed nicely and his father learned to sign well. When Ken was quite young and Diana distanced herself from the situation putting her time into other commitments, father and son became close. Now her ex-husband is remarried and living outside of town. Any "blended family", as Diana termed it,"is a difficult and complicated" setting.

Carol Asked whether Erin was self motivated, Carol replied, "she's been trained to be told this and likes that way of working now...if she wasn't deaf, definitely she'd...be further in the score [of life] if she was hearing." According to her mother, Erin exhibits creativity in many things about the house.

Carol stated that Erin is settled in school. In relation to Erin's academic ability, "she is right on schedule but she's behind of course in some of the subjects, you know like her reading comprehension isn't right on...she's got her mind set already to take what she choses...she's really emphatic about NAIT, she doesn't want to go to U of A because its' too hard' she figures."

Carol also stated that sometimes the school work and extracurricular interests have conflicted. "It's just time wise you know she does spend a lot of time on her work and that seems to be the priority in her life...she needed the math coaching, that's what spoiled the beginning [for sports] but she's going ahead in math...we keep pushing her, 'you can't just work you have to go and jump around.' "

Powerful Emotions Regarding Child

Several of the mothers referred to their hearing impaired children as "wounded", "damaged" and "different." All of these women have experienced in varying degrees long term pain and frustration at being unable to cure or to ideally equip their children through education and communication for their lives. Their strong emotions such as pain and the feeling of being burdened because of their hearing impaired child have lessened although the emotions continue to resurface throughout their experience. Frustration has also occurred repeatedly for the mothers.

For the first several years in the lives of the hearing impaired children, the attention of each of the mothers was focussed mainly, or solely on that child with the spouse and other children coming after the disabled child. They have all achieved some balance in their time spent with the other family members although several women expressed the desire to do it all over again, correctly this time.

Several of the mothers stated that too much was required of them to cope with shortly after the diagnosis of deafness was made. It is important that people interacting with mothers of hearing impaired children be aware of and empathize with the family members and keep in mind the permanent nature and severity of hearing loss.

The experiences described by each mother illustrated the effect of this sub-theme on their relationship.

Leah "It was the pouring on of all the things to be learned... When someone is that close to you and there are no remedies to make it better, instead you learn to live with it...you adjust but it never stops being painful, even the memories are painful."

Leah was totally involved with Donna for the first few years. She stated, "the kid was just a total extension of myself... when I heard that [we were moving to another city when Donna was quite young] I just about fainted, it was that much of a shock to my system... that's how involved I was." She has struggled to cope with these memories and feelings.

Carol "It's a big blow and you react... I've been reacting for ages." Carol said for the first few years, professionals would tell her to smile because she looked so upset. To their advice she replied, "When you're ready to smile you will, otherwise it's false." It took her a long while before she was able to smile easily although she was sad but not immobilized.

Carol stated, "You've got a deaf kid, and that means a whole life time, or more or less, that you think you cannot see that it won't be a burden forever. I mean you think it will at that time...it's an emotional load dumped on you...but things get in routines and all and the thing becomes lighter just because of the way you manage it...at the beginning it's just a big problem that you think there is no solution for...I could hardly stand looking at one day, week, never mind his whole life....that was the biggest thing at the beginning was just the tremendous burden, I thought it would be forever...it was initially but now it's not a burden at all anymore, you know, it isn't, I mean not for quite some time."

Carol for the first five years was preoccupied with her hearing impaired child. Carol explained that one of her traits was that she has the ability to concentrate "One hundred percent on one thing", and Erin was that focus for those first few years of her life. Less attention was paid to the two older children during that period, "Luckily they're independent and had each other...the kids went and found happy teachers for adult input and the teacher encouraged that...one of the teachers liked and helped Jane to cope with her new deaf sibling." Carol did not mind that teacher filling that role for that time.

Carol did refer to the ill feelings, discouragement or depression she felt for several years after Erin's birth and diagnosis. As well, "[you] try not to think about it...well you know we've been involved in her life, with the homework and everything I mean more so than with the other kids, well if you start thinking about it you might feel burdened."

Joan Joan stated that the frustration the parents felt when Sheila was in her junior high years was theirs and not hers. Sheila saw junior high, according to her mother, as an accomplishment and as a positive time that was marvelous, especially in grade nine.

The burden for parents of hearing impaired children, according to Joan, is limited because "these children can learn to become free and independent...different from other handicaps." Although parents may still feel the burden of their child, the burden usually does become less as the child matures.

Pam The deafness of her daughter and other family illnesses have been a burden and been frustrating to Pam. "Life itself is very frustrating", said Pam. After diagnosis of hearing loss, the professional told Pam that nothing cold be done for Paula and that she may as well go home, "so I went home totally discouraged". There have been many problems in her situation that have caused frustration for Pam, " I've raised this child since she was born and I have a little more input than [the professionals] do but they can't get that through their head...When you have social workers, handicapped children, government, the school board and medical problems you have to learn to control your thoughts and actions." She was not encouraged or supported by most of the professionals, and because of the family illnesses and other conditions in Pam's life, she has had a very tough emotional time. She has felt bitter towards many influences in her life such as the schools, however is more optimistic in regards to her own employment and lifestyle.

Diana According to Diana, "the deaf child is a hassle, frustration, pain in the ass, difficult." Diana did not mention her son as a burden or wounded but when questioned about this in the second interview she said,"No, not now, but it is a burden on the family, but I can't own it", but explained that maybe earlier in his life when she was depressed that may have been her feelings.

Much of Diana's experience has involved frustration in a variety of settings. "My experience of being a mother of a hearing impaired child is being paralysed...it's never feeling that you have the expertise to move right at the point when there's an intervention..for me the theme of what my life is...somehow its never happened with the other kids, I mean I don't have that frozen feeling, there's something special there...Well today it's a really frustrating experience and I would guess that's standard, that's the way it has been since he was newborn and tiny...When he went to [a school] I withdrew for awhile and kind of licked my wounds."

The time period of diagnosis for Diana and her ex-husband was intense and frustrating. "His Dad and I sort of figured it out about I think, it was around five months and we started taking him to doctors and it took another three months, the doctors and the audiologists and they said yes, he was deaf and he had [other difficulties] and that was corrected so we were immediately on the lookout for other associated problems." Diana, in our second interview, said that the devastating thing at that time was the, "life and death of the other problems." She said she made a deal with God that if he could live she would take anything. Diana termed this as her, "bargaining, desperate, grief cycle." She explained that , "actually an audiologist finally really confirmed it for us at nine months but it was sort of an anticlimax like 'I am terribly sorry to have to tell you this but I think your son has a hearing problem', well we had been begging people to tell us that for three months. He did a beautiful job...It is the most difficult thing in the world I think for anyone to say that to parents whatever their preparation is." Perhaps the professionals were waiting for evidence to support their diagnosis; in the mean time the parents were experiencing difficulty coping with the unknown.

"It's there [the pain], it refines and a lot of the grief process is sorted through but the actual physical grief or strain over thinking that you can't make it right or you can't build this ideal situation is still very powerful and I would guess, for most parents [it's the same]." Last year, Diana and another woman gave a talk to a group of teachers in training . "[We} got out of there and looked at each other and here we were, we had worked in the area, we were professionals, we've dealt with this all these years and we came out of there feeling like yo-yos, just like we'd been through the wringer, it's so much emotional involvement still with those issues around your kids you just can't write them out, people ask the right questions and whoop! there's all this junk and it's amazing...but that particular experience would be just what this [the research interview] is like, there it is again, I feel myself to be pretty centered, basic, well controlled, capable person but there is all that junk still around those kids."

Diana stated that she wished she could raise her children again attempting to spend more time with them and be more balanced in her attention to each. Diana's time revolved about Ken for the first few years and the other children had to fend themselves. "Of course you can't go back and make it all better. I would love to be able to go back and do it right."

Separating Issue of Mother and Child

With most handicapped children, responsibility lies with the mothers and fathers for the care and education of the disabled family member. A general difference between deafness and other severe handicaps is that the hearing impaired individual may eventually live independently. The mothers often have great responsibility and time commitment invested which decreases as the children grow older and have increased independence. Hearing impaired adolescents have been generally viewed as having greater dependence on their mothers and fathers than normal teenagers. Upon examination of the experiences of these five women, their disabled children have all mastered some independent behaviors.

Leah named the ongoing struggle for independence in the relationship with her daughter, Donna, as the separating issue. For most children at adolescence, independence from parents becomes an issue of concern.

To become self sufficient, productive members of any society, individuals must be able to care for themselves, make decisions, and take responsibility for their actions. One difficulty for mothers is to know when and if it is appropriate to become involved. "We bring her up, but Sheila must do the rest for her life", said Joan. Leah stated, "She is wounded, I can't heal her, she must do it." The mothers play a limited but important role in the entire spectrum of their children's lives.

Four of the mothers discussed this issue, giving examples of some opportunities that were created for their youngster to exercise her/his independence. Pam did not describe any specific strategies she used although her daughter, Paula, did exhibit many such behaviours. One method used by several of the mothers was learning to use the transit system thus allowing them increased freedom and mobility.

Each of the mothers and their children are at various stages of independence, partially due to their chronological ages. Diana, with the youngest child in this study, likes the challenge and has utilized available opportunities for independence. Carol does not seem to struggle with Erin's independence and Pam's Paula has developed independent behavior without what seems like direct intervention from Pam. Joan repeatedly mentioned Sheila's striving for independence and self reliance; Leah still seems to be grappling with her role in Donna's life although because Donna is now living out of town, this issue has changed somewhat for them.

Another aspect of this issue that was only touched upon by Leah and Diana is that the mothers, too, must learn to be independent from their children and family.

Examples of the mother's experience demonstrating some of the aspects of independent living are discussed.

Joan "One thing about Sheila you can't handle things for her, she's always been really very independent... she's really on her own now in terms of all that [school]...this is what she'd been trying for all along she wanted to show that she could do it, she didn't need all this backup."

In one incident, Sheila experienced ongoing difficulties with several teachers. "Finally we had to get involved [at school] which bothered her a lot because she felt that she should be able to deal with these problems herself and really in a way she should have but the teachers were not taking her seriously." The teachers as it turned out, did not understand the effects and limitations of hearing impairment on Sheila. Joan and her husband brought the teachers an audiogram which dmonstrated what Sheila could and could not hear and explained the meaning of hearing loss. " Sheila doesn't want to separate herself away from other deaf people but I guess she feels it's important to prove to people that she can function on her own because that's the area she feels really vulnerable."

Joan described another incident in which Sheila was out with some hearing friends who were following another car to a party. They lost sight of the other car and no one in their car had the address of the party. Sheila helped them sort it out and afterwards she told her mother,"it was funny none of the people stopped to think of what they could do, they were just in a big flap."

Joan attempted to ensure that opportunities did arise for Sheila to become independent. "I was very involved in Guides but I was never involved with her, I always did something that didn't have a direct line to her, because we did so many things together it was really important to stay separate from her in the activities...I tried very clearly to stay separate from her." Joan stated that her daughter had been going on group trips on her own for quite awhile.

Pam Paula has learned to be independent in some ways. She has held a part time job for over a year and a half. This has allowed her to master the transportation system and responsibility for arriving at work on time. She has also learned some money management.

Carol Carol's child, Erin is fairly independent. Recently they watched home movies taken when the family was quite young. "You know, her personality, she's such a little boss! When she was this deaf little thing ordering all the people around her, commanding.. she's just right there in the thick of things, in the middle of it all."

Carol said,"she can function on her own, she goes out by herself and shops by herself for example buying, and returning a gift she had bought for her father with no help from anyone...Erin and [a friend] go tootling off at noon hour in a car and go shopping...they are very independent."

Erin has also travelled without family or close friends such as on two two-week trips with hearing students. Extensive preparation was needed for these trips, that were organized by the school board, and Carol and her husband accompanied Erin to the orientation sessions and met the leaders.

Their family is very independent "just from all of us we sort of more or less do our own thing." The whole family, reported Carol, has wanted to protect Erin. "I remember I wanted to protect her...I had to think about it and try to let her go out on her own more often when she was young."

Diana The independence issue worried Diana whose son, Ken, was the youngest of the group. She has observed many other children overprotected by their parents which has lead to unhealthy situations. She said she has to remind herself to let her son do things and that he must learn coping strategies. She stated,"I'm separating from my child trying to let him own his problems but it's never gonna feel right, but he has to put up with some of this junk." He has learned several tasks of independence such as shopping, basic money management and the transit system. Unfortunately she says school limits his ability to be independent which she said tends to create dependence instead in the students.

Leah Leah has inwardly struggled with deciding whether and how much to be involved with Donna's life. Leah stated she established the things that she thought were important for Donna and allowed Donna to decide, for example, what clothes to wear but Leah decided bedtime.

Leah came to terms with allowing her to try on her own without involvement of her mother but,"the big struggle for me was, well, do I go along and interpret for her or do I let her go by herself...that's always been hard for me but most often I opted for not going with her." One of the areas Leah struggled with regarded the "hearing" little league softball team with which Donna wanted to play. Unknown to Donna on the evening of her first practice, Leah followed on her bicycle to watch Donna manage fine at the practice; after that first time Leah did not need to go again.

For several years Leah was one of the few people with whom her daughter enjoyed conversing because her friends did not know the answer to things such as, "Why did the Roman soldiers wear skirts?" They had many interesting conversations but it made it difficult because Donna tended to rely on her mother for information and interpretation. Leah has had very difficult decisions regarding which decisions, if any, in later adolescence she should make for Donna such as Donna's dentist appointment, and when her daughter must do these types of things for herself, "My dilemma is always the kid needs help and support in some areas and where is it appropriate and what is not appropriate anymore." Leah described when Donna wanted to open a bank account, "She thought you just write a cheque and take it to the bank and they give you money...you've got to have money in there first!"

Leah stated, "I was never a part of her way of integrating as much as she did... I don't know what she did." At the lake at a young age Donna would go to the local store to buy the items her mother requested. At a little older age, Donna borrowed books from the public library on her own, and was involved in the YWCA programs. "Donna is very skilled at and comfortable with [integrating]... she's learned some neat coping skills." Donna learned that learning to write well in order to communicate with others can be important, as well.

The struggle of independence emerges for Leah and Donna when Leah discussed a recent event where Donna used the excuse"I'm deaf - poor me" for not completing a task. Leah replied that ,"You always will be so you better learn" , but Leah said she still felt guilty. Leah holds the expectation that Donna would, and will continue to, learn to integrate with hearing society.

Leah needed, and still needs, to find her own independence. When Donna was about sixteen, Leah felt that she, " didn't know what else to do but I knew I needed something different." She decided to leave the city to attend school. In retrospect , she said that she felt she did not have the wisdom or the strength to let her daughter learn independence so she left with hopes that it would give Donna a feeling for doing things for herself. Now that she is even older, she says, "it [is] no longer appropriate for Donna to turn to mother as the fountain of all knowledge and help." When Donna left for school, "it felt right that I'd go on and get on with my life and she'd get on with hers!" Both of her children are living elsewhere therefore Leah is now living on her own. Leah exclaimed, "I've graduated." With the physical separation, the feeling of independence is more likely to emerge - for both mother and for daughter.

Theme III - Parent/Professional Relationships

The relationships of professionals and parents were a major theme in this study. The majority of the experiences discussed by the mothers related to their association with professionals. Each woman described positive experiences which were, however, outweighed in number, signficance, and clarity by nonfacilitating, antagonistic, or insensitive relationships with professionals. These latter associations were not limited to one group of professionals but ranged from doctors, to teachers, to speech-language pathologists. The individual in the role constitutes the quality of interaction.

Parents and professionals, in essence, work towards equipping, as best as possible, children for successful living in our society. Unfortunately, this relationship can become adverse when it becomes a tug-of-war of who knows best for the child. The mothers explained that it was often difficult to make a decision that disregarded or contradicted professional advice. Several mothers were treated poorly by professionals who disagreed with the mother's decision regarding what she considered the best available steps for her child.

The mothers were concerned about the confidential nature of this project. One mother stated that the hearing impaired community in town is small and she did not want repercussions from information she shared with the researcher to in any way influence the interaction of professionals and deaf individuals with her child. The other mothers voiced similar concerns. Only one mother who is no longer involved in the field of deafness and who believed her child was beyond the repercussions that were possible when her child was younger and she was more involved, was not concerned about the confidentiality of this project.

In this study, the importance of this theme of the parent-professional relationships varied from woman to woman. Because the children of Carol, Joan and Leah are in late adolescence and consequently less directly influenced by any single professional, this theme plays a lesser role in their experience. All of the women did however have several salient experiences which demonstrated this theme.

Leah When Donna was quite young, Leah observed her in an intervention class, "I didn't feel very comfortable with the interaction I saw happening with the staff and the children... I thought now why should she be treated that way [they squeezed her face] just because she has a problem, a hearing problem and that made me really think... how I interpreted it was disrespect for that little person." When Leah decided to move Donna from one program into another, she met with some resistance from the teachers working with Donna. "They didn't agree with me but I had made up my mind."

Some of the interactions Leah had with professionals were not encouraging. When Donna was in secondary school, her school attempted to integrate the students part-time. Leah stated, "The school came and said to me you know we considered this but it fell through. I was just flabbergasted.... I didn't know a thing about it!! Now did they ever consider that (a) I should be informed and, (b) that I may have more power to do something about it!" An opportunity for cooperation that may have benefited the children and the parent-school relationship had been lost.

When Donna was five, Leah met with the pediatrician who told Leah that Donna had a lack in language and potentially had other problems., "she [the doctor] had a lot of courage even in those days, [she said] that Donna's main means of communication would not be speech and boy!, you'd better get her into a manual communication program as soon as you can."

Leah discussed the importance and influence of one's teachers, "how the person responds to the kid depends a lot on how they were educated, I see some deaf [and hearing] adults interacting with kids as teachers and they are behaving just like their teachers behaved towards them...I guess it's just different people...[some] are really sensitive and respectful."

Leah emphasized that the labels of 'teacher' and of 'parent' hold built-in expectations. Parents have certain expectations of how the professionals will act and vice versa. When these roles can be put aside and the individuals meet person to person instead, more productive relationships may be fostered.

Joan In Joan's relationships with professionals, the negative influence was very strong. "I get depressed", she said, " [there are] so many good people involved and I don't understand why there are still so many problems." Joan stated that the hassles with the school have been, "Draining personally, a constant frustration...grade one [for example] was a full time job for me keeping Sheila in the program."

Joan was concerned at the delay in diagnosis and the time afterwards in which they were supposed to wait for the results of a test, for example. It was very frustrating for Joan feeling that they only had a very limited time period in which to educate Sheila to give her the best start and compensation possible, "I was aware of time ticking away, we can't wait as a parent of a [newly diagnosed] deaf child..teachers would say 'we're doing a study, wait until next year', they can't!!" Joan believed children's functioning levels are determined by grade six.

Joan and her husband discussed an early educational placement for Sheila with a principal who stated that they were lucky they lived in an area where Sheila could attend a particular junior high school. Upon later investigation, Joan and Barry discovered the school served only mentally handicapped children, not hearing impaired. Stated Joan, "You know so there we sat and thought about this for awhile and it really shocked us, but maybe it was a good thing it happened because we had to start thinking quite seriously about what other people thought of deafness and realized they did not share our feelings that the child's ability and interests should determine the course they took in life." This was one of their first experiences in which parents and professionals did not share the same perspectives.

In Sheila's grade one program, the students read books about 'Dick and Jane'. Replying to the fact that Sheila, who could already read at that time, placed the books in the garbage, Joan said, "If that's what the school offered, forget it, this is [the teacher's] idea of extra reading for Sheila. I said, 'Sheila had been reading for a year now and she didn't need Dick and Jane.'" Sheila had stopped complaining shortly after that, therefore Joan believed the teacher had stopped using that material. It was not until years later that Joan discovered Sheila had instead hidden another book inside the Dick and Jane reader. When the teacher was unwilling to adapt, the child did.

In grade one, Sheila balked at a test because she did not like the teacher who adminstered it and consequently, she did poorly. Joan now believes that the results of this test were used as "ammunition" against Sheila when they attempted to access certain programs and services for Sheila. "I thought, any teacher who would give a child like that a test, if they knew anything at all about a child they would know that there was something wrong with the test, it just didn't make sense to me."

One of Sheila's teachers who wasn't teaching her directly, decided on the basis of Sheila's audiogram that Sheila should not be placed in a regular elementary classroom. "It seemed to us she never did look at what Sheila was doing or how happy she was, she seemed to fasten on the audiogram and say,'this child should not be there'...[it was a] very uncomfortable 6 or 8 months because we kept waiting for someone to come to the door and say you are mistreating your child, and our version of mistreating our child was to have her in this program... the teacher was a very strong willed person and the rest [of the teachers] sort of sat back and said, oh well...it wasn't just the one teacher, it was the other ones who got looking at Sheila the same way."

A number of other incidents occurred such as: a speech therapist for several years treated Sheila poorly but finally agreed that Sheila could handle the situation and in effect, Sheila went without speech therapy from the ages of 8 to 12 which, said Joan, "are pretty critical years" ; in her later school years, Sheila sometimes copied other student's notes to supplement her own because she was unable to get all the information in class. Her teacher accused her of cheating, although he did apologize to her later; at a conference she attended for hearing impaired teens, a hearing impaired adult inquired about her grades and in what other things she was involved. After she told him, he replied that Sheila did not need to lie to him. The adult would not believe her until someone else had verified her story. Joan commented," How sad that even as they encourage them to be what they dream they can be, they don't believe or encourage the ones that are."

Joan explained that as a parent, "you can be objective on two levels, you think your child is wonderful and then you have to look at it objectively." As a participant in a situation, it's difficult to have all the viewpoints of a situation. "Apparently things were going on [regarding mainstreaming], that even we didn't know..of course we didn't know I guess how severe the pressure was on [the teachers]...it's hard to know sometimes what happens, when you see only one portion of the picture... maybe it gives me a not too clear perspective[because of Sheila's abilities]."

Joan recently examined Sheila's school file, "I'm glad I didn't know half of that stuff, I can't deal with it... teachers say one thing to parents and write something else [in the reports], why?....we'd established credibility with the teacher...this had gone on for six years [in the files],we were burned...I resent all the time it demanded of me, ninety percent of it should not have happened, it's hard to figure out and accept."

Joan was also concerned about the effect upon Sheila of an incomplete file and teachers who said one thing to the parents but wrote something else in the file. "Where was the child in all this?" Joan said there were no marks, tests or comments in the file to demonstrate that Sheila was coping well with the situation only the uncomplementary speech therapy reports or statements that Sheila was bored. A very different picture would have been gained from relying upon the information in the file than from what was in fact happening for Sheila in classes, regarding homework and her functioning.

Joan was irate that she never had the opportunity to present her side in the files. "Sheila tells me there's a note in the record about how Mrs. X insists...' and that this goes all the way through you know, 'Mrs. X. insists' this be done...of course Mrs. X. never gets the chance to say or give her side of the story." In one of the reports that Joan examined, she was described as a "rampaging person...we were just reacting to, not making waves... I couldn't pinpoint the reasons for the difficulties although I felt something was happening." In general, Joan stated the teachers seemed to enjoy Sheila and the teachers and Sheila's parents had good home-school communication and relationships. She explained that the professionals treated them like knowledgeable people but, "it never came out in the interviews how the teachers wrote about us."

Some of the professionals they encountered were of assistance for awhile, perhaps challenging Sheila but then, "became a big obstacle the next year, a mass of inertia." Joan stated that she did have some rewarding , positive experiences with professionals over the years. The speech therapist for Sheila's grade seven year told Joan, "I'm not sure what to do but I'm not going to give up." This woman worked with Sheila for about 6 months and gradually things began to improve although it was a difficult year for all. Sheila told Joan that she was grateful to that speech therapist.

When Sheila was young the family visited the XY school for a three week course. "I remember one dramatic incident, there was a boy that was terrorizing everybody [such as = putting Sheila's head down the toilet]. The psychologist, who Sheila called the 'wise one', somehow discovered he had great manual abilities and aptitudes..so she mentioned to all the parents about his aptitudes and you could see his mother just sort of relaxing...she suddenly realized that yes, her child had some merit...and within a week the child's behavior in the nursery was quite different." Cooperative, alert and sensitive professionals can make a difference to mother and to child.

Joan stated that recently , "the principal did say to us,'I had to rethink an awful lot of what I learned about education after dealing with Sheila because of the way she tackled her problems'." Another teacher at the end of junior high said, "you know that was the best thing you did...[when they insisted Sheila be placed into a certain program] because he said, ' you have no idea the pressure that was put on us not to put her into grade seven.'" Joan did not know from whom the pressure came .

Joan said that the professionals she liked were the ones," who spent time outside the regular hours...they impressed me...those who had a real committment of that beyond job requirements...being involved in associations and meetings."

Diana Diana experienced some difficulties with professionals. She stated that, "the teacher was really quite difficult to deal with these days...my son's teacher insulted him...and took that wonderful opportunity [through fluent communication] to destroy his sense of self worth." Another incident Diana described as, "One day I was home late in the morning and I had worked very late in the evening before and I was ill and she called and I had left messages that I didn't want to be interrupted, and my son finally called and said she insisted on speaking to me that it was an emergency. She got on the phone and started screaming at me, it's 9:30 in the morning and I was sick as a dog, about Ken not doing his homework and what was I going to do about it?...I finally had to tell her we would finish this when she was in control."

"The day I was leaving a school one of the teachers backed me into a corner and told me I was destroying his life...but it was really tacky because I treated her with respect all those years and it really hurt, plus no respect for Ken."

"I think the children are trained to be illogical", stated Diana, " then they know the control comes from the teacher's mood and then the teacher's mood controls the whole classroom and that's what gets sick in the whole field of education for the deaf...classrooms become controlled by emotion and people's emotions get strung out and get more extreme and the kids get more extreme...[responsibility] is actually beaten out of him when he takes responsibility , I mean independence initiative is the last thing that seems to be valued in the system..so you get these great independent strong thinkers and they try to knock it out of them so they'll behave..according to their standard, whatever the behaviour...I worry about what that says of how we pretend to educate teachers to work with hearing impaired kids."

"So what's heavy on my mind is what a struggle it is for such a neat child to reach his potential...how sometimes that's impeded by the very people who specialize in the care of these kids...it's probably just the nature of the communication difficulty people tend to take advantage, I believe, of hearing impaired kids. If they've worked with them for a long time there is the tendency to talk down to them and not take them into account. ...a lot [of teachers] who are extremely rigid get into this business and it bugs me. The most rigid people choose it as an occupation."

Her negative experiences with professionals, she summarized, has always been centered around rigidity, punishment and inappropriate consequences. Incidences that involved Ken included: writing 500 lines, when he did not know how to read or write, for stealing ; missing his school party for a minor infraction; and missing a school concert because he had been practising his role for the play instead of completing his homework. "So that kind of punitive junk is what I mean, you know a total lacking in terms of behaviour...a discipline philosophy...to give them some outlandish punishment...Somehow people are supporting that garbage."

Diana stated, "a lot of the difficulties in the culture are difficulties with the way they were educated...There's something my parents taught me, 'victims of victims' and I know that most of these teachers are victims of terrible parenting experiences themselves and so they come out with all that critical, negative, aggressive stuff because they were treated [that way]...it's amazing how much impact parents and teacher have and how much that controls the next generation of our society." Perhaps our struggle, Diana explained, "is to help them to get rid of that stuff. "

Regarding counseling, Diana said, "we had none, a few professionals 'pontificated'...if we had just had normalized kindergarten with lots of language input [and] put kids in a very early intervention program that was normal and spent some time on parents we wouldn't have the kinds of things we do, such as divorce...I guess primary is that focus on the family, enriching and supporting the family to be normal instead of supporting them in, what I see in most families who go through this which is a lot of pathology, I think the pathology is supported...the way we treat them is to be sick and not to be well, the family functions in an abnormal stress-producing uncomfortable manner [and are] not a well functioning machine...we train them that way." Diana stressed,"'any handicapped child, I think, the families need a lot of special intervention and we don't get it."

"I know there are teachers out there who just wouldn't consider [harming a child mentally or physically]...the positive [experiences] are obviously where people are accepted and take me for what I am and like what it is I have to offer...people who enjoy my child and were able to encourage him because he is very amenable to encouragement...I would love to send him to a private school that frankly some people I know in this business would have designed...they are just very talented, capable, child-centered people and I would just love to expose him to them instead of what he's getting now...the people I admire in the deaf community are people who have survived and triumphed over their education system, they just come through incredible odds to be capable, well-rounded, well-balanced people."

"When Ken was in regular school we had a wonderful situation with an interpreter... when I look back his best years were in a child-centered program in preschool. He had a teacher who believed children came first and hearing impairment came second and a coordinator who supported the belief. That was a delightful year, a respite... his years in regular school probably were terrible educationally although the academic reading came up and other things came up but in terms of 'formal language development' that hearing impaired kids are supposed to get I would guess he suffered some but it was so much better for his socialization, sense of self esteem."

When Diana and her husband were contemplating entering Ken into a total communication setting from an oral one, a professional person provided them with timely guidance. "A teacher was honest with us and gave us information which helped to make the decision." Some of the other parents in the program looked at Ken as a model because he was having better success than the others but according to Diana, he was still only average. "A lot of professionals are afraid to say to parents, that parents won't understand...but they will mostly...If they can't cope with it then, try again later on with another professional telling them...be straight....a lot of parents aren't given straight information and how do they deal with that?" Diana questioned how anyone is able to make an effective decision without accurate information.

Pam Pam said that when her child was diagnosed as hearing impaired, the doctor told her, "I might as well go home and forget it, my child is deaf and there is nothing that can be done about [her hearing loss], I could buy her a hearing aid if I wanted to but it would be throwing $500 down the tubes and there would be no sense in it...so I was just so upset I didn't know which way to turn or what to do, so I went home totally discouraged." It was not until her daughter, Paula, was about five that a public health nurse doing routine immunizations suggested that Paula be tested again. Pam agreed to have Paula retested even though the professionals, when Paula was first diagnosed, had told her it would be of no use, "I says, sure, go ahead if you think there is a chance." Paula was subsequently placed in a preschool program and fitted with hearing aids and she continues to communicate orally. " If they had tested her properly when she was born or even when she was two, I mean they didn't have any indications whatsoever when she was born, even the specialists there, they never suspected anything like this with all the tests they did so I don't know how this idiot ...come up with his conclusions [that nothing could be done]...she missed three years of hearing people talk and knowing words, she would have had a lot better start."

Pam had many experiences with professionals, or "those in authority", as she described them, that were not pleasant. Pam defined professionals as, "those people who claim to be professionals when they don't know, they have no heart and no feelings and they go by the book and rules and people themselves mean nothing, [those] who think and act like an authority." She stated that,"I hate people in authority...I hate professionals." She disliked many of them because they, with a little training, thought they have all the answers. "In most cases the people in the know seem to think they know everything...I know how to teach your hearing impaired child and now I know all the problems and I know what to do...they've gone to school for a year or two or whatever it takes above and beyond the regular training...they seem to as soon as they get that degree or stripe on their hat or whatever it takes they seem to, everyone else is dumb they know everything...who cares what you think, who cares how you've handled it all these years, who cares, and that ticks me off!"

Pam stated that many of the professionals she has come into contact with do not take the mother's experience or knowledge into account when deciding treatment or making placement decisions. "I've raised this child since she was born and I have a little more input than they do but they can't get that through their heads and I know a little bit more about her the way she performs, her habits and what she's getting at and why she's doing things and they all know, 'we know, we know, we know'."

Many of the professionals with whom Pam has come in contact do not understand the differences in the people and in the situations therefore there is a need for treating each case individually. " And I can't get it through their heads that every kid is different..[they think that] everybody is the same, every situation is the same and this is the rule and this is what the books say and that's what we do...but you have to treat every situation different, every person different...whether it's their lifestyle, color, education, upbringing, everybody is different, better treat them that way."

After being questioned specifically about positive experiences with professionals, Pam said she had had some, "this social worker I've got she's actually treated me like a human being...the worker I had before her was really good if there was a problem she let me explain whatever the situation was and she says,'from now on this is what you got to do this and this and this to keep people quiet' so I did it you know... [a doctor] was good that way when a person had a real problem she did things, she didn't care she just did it, her reputation, her career, she couldn't care less if somebody needed help she was there." Pam stressed it is the person, not necessarily the role, that makes for pleasant or unpleasant interactions.

Pam summarized her interaction with professionals, "There are professionals who really want to help but others who are blocking the system."

Carol The majority of Carol's experiences with professionals were encouraging because the professionals throughout the years have provided them with guidance and support. "We relied a lot on the professionals..you entirely rely on guidance...it's really kind of interesting how these choices get made at that point... you know you pick your professionals and then you believe what they say, that's the way it goes. I mean, heavens, we could have gone any which way, we just walked this way because they told us to and it sounded the best way, oral, also and at that point you really rely on, I think, the professionals."

"But besides guidance like that you rely on them for emotional support and if they happen to be good, so you just sort of just like to see them regularly...that's what I want to tell you emphatically, it was the professionals [that supported us] so it was the professionals absolutely. They gave the moral support to carry on with this program and just keep on going, their function is besides teaching, it is support, it is very important."

Carol noticed that as Erin grew they had a decreasing need for the input by the professionals, "and then pretty soon you don't need them, it's like any kind of teacher you need them for quite awhile and then you don't need them anymore" .

The itinerant teacher was crucial through elementary and junior high. "They helped to educate the teachers, do inservices and her enthusiasm rubbed off on the other teachers." As well Carol explained that these professionals have a somewhat more objective view of the situation while hopefully realizing that every situation is different, requiring various methods be used.

At the time of diagnosis, Carol's doctor attempted to allay her fears of a problem with her child, " the pediatrician kept saying ...so she's not talking! Calm down....We were wondering why she wasn't talking that was the only thing we were wondering about...she was perfectly fine otherwise she was very alert and except you know we had the other two girls first and we knew, sort of why wasn't she talking...then we tested her ourselves, like banging pots and paper bags, and she didn't hear them." (It was interesting to note that Diana, too, did, "crazy things like breaking paper bags when Ken was asleep and banging pots to see if he was disturbed, of course, he didn't.")

"I had a friend who did [notice her uneven walk] and she was a physiotherapist and she said 'well you should have her hearing tested'. She observed that from how she was walking....I somehow didn't pay attention to that [her walk]." The pediatrician when she realized she was deaf she right away put us in contact with the project", stated Carol. Although the doctor did not heed the parent's earliest warnings, she was willing to assist once Erin was tested.

Theme IV - Educational Program Considerations

At the time of this study, the educational placement of each adolescent was different. Each mother had criticisms and some praise regarding the programs in which their children had been enrolled. Some of the educational settings experienced were highly praised by the mothers although many more programs were described as nonchallenging, unpleasant or nonfacilitating for the children. One of the overriding concerns of the mothers was that the ideal program for their child did not exist yet because of the diverse needs of the children and families for communication, suppport, and skill development, one wonders, as did several of the mothers, whether the ideal program can in fact ever exist. Alternative programming for the students must, however, remain available to meet the needs of the population.

The parents' role in educational programs remains limited because their decision-making power is often slim. The parent is often one of the few, if not the only, adult who is continuously involved in attempting to access the required services for the children. Instead, often the bureaucracy and professionals hold the power to make the decisions regarding the available options and programs; this can sometimes be an unsurmountable obstacle to parents.

The salient features regarding educational programs are discussed by each individual.

Leah "Alternatives are a must", Leah stated, "I hope they will keep the options open. I hope that the institution of a school won't just suddenly take over everything and substitute one institution for another... it would be nice if there were alternatives for the kids....there are some kids with the great discrepancy between intellectual potential and their academic achievement... This is just absolutely ridiculous...There must be a better way of assessing the children." Leah also explained her limited input into her daughter's education, "When I got to [the school] my role as a decision maker stopped, you know when you get on track here, unfortunately there aren't a lot of options...there was no other decision making process because there weren't any other choices at that time".

Diana Diana is dissatisfied with her son's current program. "I'm just about ready to take him out of school...I have been seriously thinking about home schooling for the next six months." During the second interview, Diana stated that home schooling was something like a dream for her, just an escape because she was a single parent with a full time job who did not have adequate time or resources for home education.

One problem, according to Diana, concerns the funding of the programs. "I have friends who have multi-handicapped kids who have them in the regular school system and have [all sorts of services], And I look at the struggle with Ken who just has the one basic impairment which is severe communication, it's a terribly severe impairment... and [the school] will not pay for an interpreter in the school." Diana also mentioned political fighting, funding cuts, and monies that go to children who need everything with little remaining to those who need few services.

Joan When Sheila was in the early grades, Joan related an experience that, "It seemed to us that quite often when she was in the special classes I don't think she was ever challenged, which was one of the big flaws...I felt that because she didn't fit the stereotype didn't mean that she shouldn't be educated...and I know I felt quite bitter the Year of the Disabled because I felt what she was getting certainly didn't qualify as education by any means and yet the UN charter of Rights [stated that] every child should be receiving an education, that's one of my frustrations" Although frustrated with the programs, Joan also felt that her daughter needed the strong basic foundation for later learning. Joan placed her daughter initially in a special class because," I think it did give her a chance to consolidate her language skills...and we felt she was going to need more support in the language development area...there was no program available that was suitable for her."

"So many of the children don't ever seem to really reach their potential and I don't know what- they start out and seem so bright and seem to have so much ahead of themselves that never develops...It seems you can go to one school and have a marvelous social life and a poor education or you can go to another school and have a good education hopefully and not such a satisfactory social life... At the time [when we were looking for schools] we were told the average reading level was around grade 6 or 7 and that didn't seem to us to be in any way an adequate preparation for life."

Choosing programs is an individual thing, Joan stressed , "I don't know how [a program] could meet all of the children's needs...the kids are all so different with different needs." Joan cited the example that within the same school, one child has no supports, one has a tutor, and one has a full-time aide. More that one way to cope with the situation exists.

"It was just a bureaucratic maze it seemed to us...it just seemed to be a tremendous mismash down at the school board...the lines of communication [had problems]. At one point the hearing impaired program seemed to come under about three or four different associates depending on what aspect of it you're talking about... Frustrating, I think we reached burnout." Joan stated when Sheila began high school, "nobody came to do an inservice with the teachers, nobody knew anything about deafness [although there was a deaf student years ago] so Sheila in effect was doing the inservicing with the teachers."

There were many difficulties and successes with mainstreaming according to Joan. "We had a lot of trouble getting her mainstreamed because people said a child with such a profound loss should not be mainstreamed." Eventually Sheila was mainstreamed but, "she still had a lot problems with teachers not with her academics, and with people who were no longer involved with her, it wasn't her regular teachers." The first day of classes in one of the schools, "she was so frustrated she cried and was mortified", when the teachers asked Sheila to report to a certain classroom which was different than what had been previously arranged. "When Sheila finally became mainstreamed, she suddenly discovered what kids were doing she really lit up...this was something really neat other people were doing the same things she was, she wasn't alone, she wasn't strange, she wasn't anything, they were all doing the same things and she found out that she could do things very well, which she had no idea of before." She was involved in a structured program in her first year of mainstreaming which helped tremendously and Sheila coped well.

"One of the difficulties I guess in mainstreaming a profoundly deaf child into a school system is the social aspect. Sheila had a somewhat isolated social life at school but she was also involved in many other groups. "As her peers start to mature", Joan stated, "they become more accepting of her. She didn't have trouble with junior high and social life, she saw the kids at school and felt comfortable."

Pam Pam did not discuss many incidents regarding the education or educators in her child's life. She told of one incident that happened when Paula's aide was not doing her duty and the grants for her child were not being used effectively. Pam went to the principal and, "went up one side and down the other, he just kept doodling on his paper...but there were changes made." She placed Paula in the regular school system which Paula has been in since then, although she is currently experiencing difficulties.

Carol In general, Carol, in regards to her daughter, Erin, was satisfied with the program content and delivery. Carol was concerned about the quality of education and availability of services for all hearing impaired children as demonstrated by her involvement as an advocate for programming, but this theme was not as salient to her as it was to some of the other women. She did mention that in the programs," deaf kids work so much harder to get through a day...the energy is so great they put out, therefore they are really more tired than others and not as able to get into the community." and if you're in it you want to go." In community events, the conversations of the children in which, for the most part, the hearing impaired children were not included and "the fraternization of the kids [her child] was never in the group", are as important to playing in the community events therefore Erin was not as involved in community activities.

Theme V - Communication

Deafness, as previously mentioned, is primarily a communication handicap. Language and communication were deemed crucial by the mothers; the vehicle of communication was of secondary importance. At the time of the study, three children use the oral route and two of them, a manual one. Diana moved Ken into a Total Communication program in which he has done quite well, and Leah believed that communication by any and all means was the key. Both Diana and Leah sign with their children. Joan explained her daughter was too impatient with her family's slow signs so insisted they talk to her instead, and Carol and her family have utilized the oral method which seems to have met the needs of Erin. Pam did not mention language and its necessity or influence although she wanted Paula to be placed into a educational setting that utilizes sign; she, herself, had not learned to sign.

The position of the mothers on sign language was favorable. Only two of the women have learned sign language themselves, but they all advocated its use if that was their children's choice.

The fluency of commmunication of the five adolescents was based upon the mother's appraisal. Regardless of the method, all the adolescents are considered to have fluent communication except Paula who has basic language skills.

It was noted by several of the mothers that communication was the prime responsibility of the hearing impaired children; other people expected them to accommodate themselves to the form utilized or required by the person with whom they were communicating. Several of the women also expressed how simple and easy learning language had been for their hearing impaired child's siblings.

Descriptions of their experiences and methodologies follow.

Joan Joan stated there has been no communication problem in her family unit. She said they had been prepared to make the shift to sign but because Sheila was impatient with the family when they were slowly learning signs demanding that they talk instead, they used the oral method with her. "I'm not against sign language...she wanted to talk...I didn't think I was depriving her." Other professionals in the field constantly encouraged them, some gently and some not so gently, to learn to sign.

Joan believes that language is not necessary for thoughts. As a toddler, Sheila had a number of ideas and wanted to explore her environment before she had the language to communicate her intentions through words. Sheila put words together such as , "Sara" for her blond friend, and "bird" for the angel's wings to make "Sara-bird" symbolizing angel.

Joan, when discussing Sheila's younger brother learning to use language, observed that, "language development was easy, effortless with her brother... with a deaf child it all must be planned." Joan realized how quickly her 'normal hearing' child learned language when compared to her hearing impaired child.

Carol Carol stated that they have had no problem with Erin's ability to communicate. "She communicates orally so there is no problem...sometimes right at the beginning a new person has a bit of trouble right off the bat but it doesn't take long, ten minutes, and they can understand her...it's a lot of work being oral...we didn't consider manual since we heard the word oral." Being oral to Carol, however, meant that her daughter, Erin, "did not really fit except with another oral person...I know she will learn the signs."

Diana Diana and her ex-husband initially decided to pursue the oral route but, "Ken had a tendency already toward total communication and sign language, he was very visual...[in the oral setting] there just wasn't enough language so we moved him into the Total Communication program at four [years]...he blossomed and developed all kinds of wonderful language, and has always been sort of very expressive and he uses everything, he is very dramatic and um, flexible so that if you like to write with him, then he will write and communicate that way and if you want to try lipreading that's how he'll work out, if you want to learn sign language he'll get out his books, and teaches you and takes [his books] around to the neighborhood, it's kind of like an urge to communicate and I see him as soliciting communication, and I know all our neighbors have all our sign books, he's placed them all over their houses, the Joy of Signing is gone forever."

Ken's two brothers communicate with him, one by fingerspelling and one by fingerspelling and with signs. "One is better than the other", commented Diana. Ken's relatives communicate with him through lipreading, and writing long letters. When he goes to visit his grandparents, they keep a sheaf of notes in which, according to Diana, "they banter."

Diana stressed that, "most people in Ken's world expect Ken to come to them...The only person I can say beyond me... and his dad of course, who's really been good about getting committed to sign and using it well, would be his little friend, he's developed into a good friend and has a lot of energy and learning to sign well, I mean he's good, he can basically interpret for Ken and a lot of it is fingerspelling, and speedy fingerspelling...My sister also signs beautifully."

Diana said," I think an awful lot of the other kids in the oral programs were quite deprived and they sort of put up with that deprivation to sacrifice it to the 'god of speech' and I believe that speech is vital and really important and yet a lot of parents are not understanding that infrastructure of language is what's really vital, speech is wonderful, its incredible..but it is a visible sign of what's really needed."

"In some ways there's an implication if your child doesn't talk is that you haven't worked hard enough and I worked pretty hard." In answer to the question, "how do you feel about that implication?", Diana replied, " I hate it, I hate it, you know, I think it stinks, you think if it's hard on parents it's even harder on the kids who can't perform because some of them can and some of them can't." She discussed some of the programs-working with very young children keeping them on a chair for hours, and mothers watching their children from behind glass windows. "If you were doing things right the child would be right...I failed, I've produced this handicapped child... it's not true but I have to cope with that attitude", said Diana.

"There's always a grieving period, I think, for parents when the parents realize their child isn't going to 'talk' and isn't going to talk the way they'd like them to, and that was a heavy decision...it's fine I think maybe I prepared myself pretty well, I was taking sign language before I had him in the program and it was easier to see in other kids than it was in my own that he needed the sign."

Leah Leah and her daughter have fluent two-way communication through a sign system, thus for them communication is not an issue. Leah did mention that, "I don't know [American] sign language and that is one of my next goals because...it's the quickest, most effective way to communicate...maybe our old method of communicating is O.K. though."

Leah discussed her own limits with manual skills in the past as well as now. Several years ago, after visiting with deaf parents of a deaf infant; she left their home saying, "I thought I knew sign language. They didn't understand what I was saying. What is going on?" This was indicative of her ongoing frustration with mastering sign language and making the distinctions of a sign substitution system from '[American] sign language'.

Leah related the experience in which her daughter, while still in an oral program, visited a signing classroom while Leah discussed her placement with the school personnel. "That was a kind of experience that sent me back on my ass to say the least.. she [fingerspelled her name] I just went, my God!... because the impact that situation had on me was...what have we been missing!"

Theme VI - Support

Support by others is an important concept, yet difficult to measure and define. Each person has varied sources and requirements of support although without support few of us would flourish.

The mothers in this study have varied and common sources of support. Pam's only sources of support were her eldest daughter and her boyfriend. Joan described the closeness and support of her husband and children and the many activities they have shared together. She also was, and is, very active in parent groups. Carol, her husband and children have also supported each other; the professionals, parent groups and her Church also provided Carol with support. Her children, friends, other professionals and parent groups supported Leah through the years; as well, her parents were concerned but lived out of town. Diana had the widest base of support which included her children, immediate family members, friends, relatives and professionals.

For three of the women, a parent group gave them information, personal support and a vehicle through which to lobby. Their involvement varied depending on their purpose for becoming involved and the age of their child with involvement generally decreasing as the age of the child increased.

For the two married women, their relationships with their spouse generally seemed to be satisfactory. The three divorced women independently agreed that deafness was not the cause of the breakup of their marriage but may have been a contributing factor.

An important aspect of support that came to light was described by Diana. She and her friend supported each other although their philosophy regarding the education of deaf children was at odds. Their friendship is an example to the power of supporting each other personally beyond individual philosophical differences.

The spectrum of support for each mother is described from the available information.

Pam Pam stated, "I've had a lot of sympathy but my family can't really do much they're [out of town]." Regarding her family, "They care but they don't care, I've asked my family to come and visit and they can't come...they go [elsewhere] on their holidays... always an excuse...I don't blame them for it but I've been away for years ..they just don't visit me although I go back to visit for weddings and funerals."

Pam briefly discussed her marriage. "The problem is I got attached to him, and then [you] do what ever they say." Her marriage ended in divorce, and she is currently involved in a long term relationship. Pam seemed to be bitter about her ex-husband, describing him in unfavorable terms. Pam discussed her friend, "He's there for me... he went with me [to shop, go to the doctor,] that was the difference because before I went alone."

The relationship between Paula and her sister is not certain according to their mother, Pam. The older child has had numerous responsibilities for several years in running the house. When asked about the effect of Paula's hearing loss on the sibling, Pam launched into a story on the eldest non-hearing impaired child's many other difficulties; she did not discuss their relationship.

Joan Joan spoke of her husband in equal terms. They have supported each other and shared the struggles, frustrations and triumphs in their lives. Said Joan, "When I say 'I', I mean 'we' because my husband has been very much involved in this...it's not just me doing it, in fact I don't know if we could have gotten through it if the two of us hadn't been in it together."

Joan stated the relationship between Sheila and her brother, Robby, is good which pleases her. Joan believes the age gap between Sheila and her younger brother has buffered their relationship and somewhat eased the problems. There has been more demands on Joan's time with Sheila than for Robby. Joan and her husband over the years have discussed with Robby the differing amounts of time spent with their son and with their older hearing impaired daughter. They discuss it with him, "So he'd be aware that we were aware." An incident with Robby when he was quite young was that he thought that when he closed his eyes his mother would stop talking; it worked for his sister but not for him! In the last few years, Robby has required more of his parents' time and Sheila, increasingly less.

Both of Sheila's grandparents live outside of the city and with one grandma who does not understand Sheila's accent, they have a good relationship on paper which does not match their in-person contacts. Although the grandparents are concerned and supportive, it is difficult when they visit because they do not understand lipreading. One grandma was good with small children but unfortunately , they don't see each other often enough to establish a firm relationship.

Carol There is a great deal of interaction amongst Carol's family members in relation to Erin. "Everybody is willing to teach her whatever, they all contribute something to her, they are all different things...she's gained from [one sister] in the past a nice willingness to try things...it was through her encouragement that just, 'give it a try and if it doesn't work O.K. and if it does fine'...she's also very patient with Erin's work...some of us get impatient sometimes...she has very, very much patience with her to be very slow and methodical and careful, Erin usually tries for her help first and if she is busy then [she asks the rest of us]...and my husband, he encourages her with their interests... he's just given her guidance and incentive, takes her to stores and fusses over these things and Erin is really developing a good interest in it."

Carol stated that the children have, " a good relationship... the two sisters are very protective of Erin, a bit bossy for her...you gain a solidarity [as a family] you've got this child you all want to protect her, you've got a common thing here I think that's about the thing that we most have in common regarding her." Carol says that Erin will sit at the table and tell the other girls,"what's wrong with them, you know, in the meantime she forgets about herself...the sisters just sort of grin and bear it."

Sometimes Erin reminds the family to be patient and defends herself from them when they tease her or leave her out of the conversation. "A negative trait of the family is impatience...we must be reminded...sometimes it's really hard, they all come home from busy days and all want to talk at once, well sometimes that's really hard on Erin."

Carol stated, "What we have got from her, gained from her, living with her and we have learned so much, I don't know, it teaches us to appreciate everybody for what they are". Carol described the interaction of her family as "independent." It seems they have each had their own responsibilities to carry out but share through helping Erin with homework, going on family outings and other kinds of activities.

Carol said,"they [my family] are [here] but we only see each other more or less on weddings or funerals or things like that...his family are not in-town so we don't see them often...Our family certainly wasn't interested in supporting us, they were scared to death of us, they kept their distance, you know it wasn't that they probably didn't want to but they couldn't, they needed support, too." The relatives, according to Carol, were "mixed up families" with their own problems; deafness was to them one more difficulty for a family member. Carol's family was happy that, "we weren't floundering...we had to show a secure front for them therefore we depended on the program."

The professionals provided Carol and her family with the support. Carol explained that in regards to her support, "I got fallout...I got emotional support from the professionals." Her primary support network consisted mainly of the professionals involved because of Erin.

Carol stated that there seemed to be a reason people got involved in the parent groups. "But you know I think you only do it when you've got a particular need you know when your own kid is needy for something or other or the school isn't shaping up you get involved for a reason...our reason was that we didn't have any contacts here...I really didn't know a soul here with a deaf kid and you just have to meet somebody, you have to know some people, so now we know some parents."

Parent groups for Carol and her husband served a definite purpose. One was socialization. They met others and heard their stories and perspectives. "[We] had a couple of social occasions you know...we invited all these parents and their kids to a social event, we had a few of those, a couple of them we had one here and all the people came, and the kids like that, they enjoyed meeting each other on a social level...The parents talked with each other, and the kids talked and played games...nothing happened really it was just a meeting with each other and that was nice."

Leah Leah said that the support from her family mainly went to Donna, her hearing impaired daughter, and not to Leah. The family depended on her for communication and disciplinarian," I did it, I did the best I could." The relatives did not learn sign language but they communicated with Donna in other ways, "she was part of the family unit through gifts and hugs and cards." Leah stated that it was more important to her for Donna to learn about her world and people than it was the family to learn sign language.

Leah seemed to feel that she has been too involved and central to Donna in relation to the family. "Perhaps if I had stepped back", she said, thus creating a need for communication among them, they might have learned. When Leah did leave the city for a longer period of time, Donna developed communication with her grandparents through writing.

Leah described her relationship with her daughters as, " Terri was a joy; Donna was my teacher." Because she was the only parent, " it makes for a very different relationship amongst and between [them] and because of that Terri [who is several years older than Donna] felt some responsibility." In retrospect Leah describes how she felt towards her oldest as, " a bit of a partner like if there was something I wanted to talk about, Donna or something, I would talk to Terri and at times I'd be aware I was doing this and think that that's not fair, and yet it seemed natural as well." She qualified this by saying that it was a two-way street and that she would tell Terri not to worry but she wanted to be involved. "Terri was the buffer between us...and I felt badly about Terri being the buffer for the neighborhood and in the family...I didn't realize it until it was pointed out to me by someone else just recently...Terri can get along better with Donna than I get along with

Donna, she can get along with me better than Donna can get along with me...Terri defends Donna from me - and there's that buffer relationship again."

Leah's martial relationship was not a current factor in Leah's life. Her husband moved away when the children were quite young and she did not mention any other relationship she has had.

Leah described the relationship between her two daughters as similar to two normal sisters. "Donna was just her sister, and 'go away you're boring', and beat her up or whatever sisters do...Terri feels absolutely free to criticize everything Donna does, she's too fat, she does this, she does that but anybody else dare!...whereas Donna is the typical younger sister, she just simply adores Terri... so they certainly look like a lot of sisters."

The mother questioned the communication between the girls. "I don't know how Donna understands her sister [when signing], I certainly don't....I thought it was important not to insist that Terri learn sign language and I never interfered with the communication between them unless Terri asked me specifically what is the sign for this." When Leah was out of town at various times, Terri has been very good to Donna and involved her in other activities.

Terri, thought Leah, would act as Donna's interpreter of the world for things like,"running with the kids in the neighborhood", but would not counsel her. She stated that Terri is "personally involved but I don't think she's one of these people that are going into education for the deaf or become an interpreter or anything like that."

Leah discussed some of the benefits of parent to parent support. "Parents could get together and talk about some of the issues and clarify things for themselves, have a discussion group and a self help discussion kind of therapy."

Diana "My mother was terrific and she called herself brave little tailor, she mended all our clothes for years which I had not time to sew and she'd come and iron and stuff. At various points we've had a crisis... my dad...would drive over to Ken's school and get him and if there was a transportation problem, he'd help out...during my separation as well I couldn't have survived without them, so yeah, my parents were a really big part of it. They are now retired... in the early years especially, they were a really big support." As well her sister lives in town and has been supportive over the years.

A number of friends and other professionals have also supported them. "They support Ken, I mean it's because they are connected to the area there's all kinds of support coming for Ken, too. There's a biblical saying, 'a crowd of witnesses', and I really feel that Ken has a crowd of witnesses in some way at least support him philosophically in getting through his world because it's a struggle, it's really an intense struggle."

One of Diana's friends has had an incredible impact on her life. She stated, "We have some different views primarily about sign language and about the deaf community, and so she's both been the person who has gotten me where I am today and I don't think I would have survived sometimes without her and we have all these different views as well as the same views...When we talk at home or out socially, one of us is calm and facilitates the other, the other one you know will dump about whatever is going on with their kid and get all heated up but when we both give a talk, of course, we both heat up so it's stronger."

Ken, too, has developed a good friend in the neighborhood over the last two years. "That was something that didn't come for many years. I didn't think that he would ever make friends outside the deaf commmunity because of his speech, but he now has a delightful friend that he does all kinds of regular boy-things with." Ken still has problems though. "He fights with kids on the bus and he has all kinds of personality conflicts with people and some good times too. Lots of friends that he really likes to talk to on the phone...I prefer him to be with hearing impaired kids as well as hearing kids."

Diana believed Ken's brothers were pushed too much when they're little and this has created many of the tensions for them. Diana is now trying to make up for it to them although, "I think they resented the focus...but they sure got cheated out of a few years of their childhood, and of course you can't go back and make it all better, I would love to be able to go back and do it all right."

One of the brothers was doing speech therapy with Ken when the brother was about five and Ken about one and, "that built some resentment in him, both my kids because I was busy with Ken's deafness and [numerous other] specialists in his first year was visiting their home, trying to prepare for all these people to come, and I've never had to deal with a social worker in my life, suddenly we have a problem and all these people focussing [on us]... I didn't know their teachers, and other people in my family got my [other] kids to and from school, I almost didn't know where one of them went to school, I was so isolated from these older guys and so much was going to Ken because I was driving him to school two or three days a week so I think that affected them severely in terms of them just not [being]a mother there who had much time."

The brothers are, however, more aware of handicapped people. Diana stated, "I think they're also more sensitive to being with special needs than the average population, I mean there are benefits, and in both cases I think they have a lot of respect for what Ken has gone through...well I don't know quite how to put this, I guess I fantasize that they may be quite responsible about having children, knowing the complications of having kids, that's a guess I have, that having children will be a serious thing for them rather than an [easy] choice."

Describing the relationship between Diana and her ex-husband after Ken's problems at birth," we were both too busy to ever see each other...the only time we had sitters was to go to meetings." The only time she could remember being together alone with her husband in four years was at a breakfast in another city for a conference on deafness. Before Ken started grade one, Diana and Ken's father were divorced. Although they rarely see one another, Ken and his father have a good relationshp.

Groups, Diana felt, generally work well for people although she has not been very involved in them preferring one on one interaction instead. She has, however, tried, with another woman to initiate some parent sessions, meeting with moderate success.

Summary of the Themes

A traumatic event in one's life, such as having a handicapped child, seemed to provide an opportunity for personal growth and development or alternately, a reason to withdraw, regress, or resign. At different times in their lives, the mothers have done all of these things. These mothers of hearing impaired adolescents experienced personal growth through increased decision-making power, career alterations , and taking the roles of interpreter, supporter, teacher, and advocate for their children. This growth for the single parents in regard to their decision-making power, was probably also due to becoming the head of a household and having full responsiblity for themselves and their children.

For most of these mothers, their children's adolescence has been a time when their early decisions could be reflected upon as to the appropriateness of the decisions made when the children were young. All of the children have experienced success although aspects such as their children's social functioning and friendships were likely not as well developed and successful as the mothers had hoped. This may have been a function of the deafness, of adolescence, or of the nature of the children.

Relationships are an essential part of life and part of the key to participation, growth, and development of the person. The mothers of the hearing impaired children have had strong bonds with their hearing impaired children that have continued to develop over time. The permanence of their children's handicap has contributed to the parents' long lasting and recurring feelings of pain and frustration. The degree of independence shown by their children and initiated by the mothers' role in learning and exercising this behavior is part of the theme of relationships of mother and child.

The relationships between parents and professional people is also a very salient theme for the mothers. Experiences with professionals have been supportive and pleasant at times, at other times difficult, disappointing, and frustrating. The person in each specific situation is crucial to the nature of the experience.

Although the ideal program does not exist, the educational settings in which these hearing impaired children have been enrolled seemed to have met the majority of the adolescent's needs in all but one case. Throughout the past years, all of the mothers have been involved in programs in which they have felt comfortable and ones in which they have had some great concerns.

Support to the children and to the mothers, as perceived by the mothers, varied widely among the women. They all had had some type of continuous support but who provided it and in what ways was different amongst them. The majority of the support was given from one source, such as a spouse, a professional person, a child, a family member, or a friend. Other people in their lives provided aid in varying degrees. Although the mothers did not as often discuss this theme as several other themes, the presence or absence of support affected their experience.

This study described a number of concerns and has also raised many questions about the experience of mothers of hearing impaired adolescents. Contrary to much of the literature, it seems that these mothers have generally coped well with their respective situations in raising their children. The high incidences of emotional and behavioral problems cited in the literature for hearing impaired adolescents have not been observed in this study; therefore, perhaps the children of these mothers are not typical of the hearing impaired adolescent population.

The current stage theories cited in the literature generally address the emotional reactions of the parents for a short period before and after the diagnosis of their children's hearing loss, but have not focused upon the long lasting frustration, pain, disappointment and adjustment process of the mothers in relation to their handicapped children. The majority of research has studied the development of mothers and disabled children who are experiencing difficulties in coping with the situation but more attention must be paid to exploring the well-functioning family unit and its members.

From the successful functioning of most of these children, according to their mothers, one specific communication methodology cannot be recommended for use. Fluent two-way communication is essential for appropriate development and fulfillment of the individual.

CHAPTER VI

DISCUSSION AND CONCLUSIONS

The summary of themes located in Chapter 5 briefly reviewed the six themes that emerged from this study including: the mother's personal development; her relationship with her hearing impaired child; parent-professional relationships; educational program considerations; communication ; and support. The final chapter will discuss the limitations of the study, the effects of bracketing upon the research process and future considerations derived from the treatment of the themes including recommendations and areas for further research.

Limitations of the Study

Certain limitations exist which must be considered. These have included: dependence of the quality of the study upon the researcher; difficulties in replicating the study; inadequate resources of time, money and personnel; limited number of appropriate participants; and acceptance of the experience of the co-researchers.

The quality of this type of study is heavily dependent upon the researcher. Researchers must reflectively judge the data to distinguish relevant components and place them in an intelligible order (Wertz, 1984). There was a vast amount of data for one researcher in this study to collect, compile and sort through. The responsibility for allowing the themes to emerge and to draw conclusions lay with the researcher as the primary research instrument, although other people were of assistance through their advice and reactions to the material.

Because of the reliance upon the researcher for the organization and results of this type of study, the results might be difficult, though not impossible, to confirm through replication because problems exist in attempting to replicate a study that uses the descriptive method for examining the experiences of humans. Barritt, et al, (1983) stated, "It is difficult to replicate any research where people are concerned". Through utilization of the bracketing process and description of the process used to uncover the themes, this limitation can be lessened.

The limits imposed by inadequate resources of money, time and personnel influenced the depth and scope of the study. Because of these constraints, only two interviews were held with each of the five women over the course of a month and all of the participants lived in the city. With several more researchers and an abundance of time, co-researchers might have been interviewed over several months, and observed in interaction with their hearing impaired child and other family members. Discussion with other researchers over time could have assisted in further developing the meaning of the experiences to the participants and to the researchers.

The researcher must paradoxically understand the phenomenon before doing the research (Wertz, 1984). One must know about it yet attempt to 'unknow'. The researcher attempts not to lead the interview yet at the same time to try to uncover the range and meaning of the experience. For this project, a survey of the literature was completed prior to the interviews and a more in depth study of the research was completed once both interviews with each mother were finished.

From the exploration of the experiences of mothers with hearing impaired adolescents, many commonalities underly their varied life experiences from which six main themes emerged. Similarities may exist between these themes and those that may be culled from the experiences of mothers with normal or other handicapped children. Further studies would have to address this issue. The phenomenological research methodology does not attempt to determine the causes of certain experiences, but instead examines the meaning of those experiences to the person therefore whether the mothers' experience in this study occurred due to their children's hearing impairment is unknown.

There are, however, several issues unique to the mothers of handicapped, specifically hearing impaired children, as compared to parents with "normal" children. One of the issues is communication. Language learning is often the main energy focus for mothers with hearing impaired children yet normal children somehow "learn" to use language even without special direct intervention as noted by several of the mothers. Mothers tend to have greater involvement in education and with professionals than do those whose children follow the normal educational route. Personal growth of mothers with normal children occurs but as two mothers who have also raised normal children stated, "I was stretched emotionally, physically, spiritually and intellectually beyond my limits" and, "you grow very much more than if you had normal kids." It would seem that the mother's, and perhaps father's ability to access programs is a factor in determining the quality and quantity of services the child receives. If the parent is unable to utilize the proper channels, a possibility exists that the child will suffer from a lack of appropriate resources.

Co-researchers must be centrally involved with the phenomena, be open and willing to share their experiences with the researcher to become involved in this type of study. Not all individuals are willing to make the personal investment required in this research, thus there are fewer participants with this specialized nature who may be studied. People who do not meet this criteria need their experiences tapped in other ways. All of these women in this study were fairly open to the researcher and having lived with their adolescents all of the children's lives; they are indeed centrally involved.

In qualitative research, the researcher must accept the co-researchers' description of the phenomena. Because the mothers accepted their role as co-researchers and the criteria described for participation, their experiences were considered appropriate data. The accuracy of the co-researchers' self report is affected by their self-awareness, their ability and willingness to share with the researcher, their personal motivation for being involved in the project, religion, attitude, and education level; these aspects are difficult for the researcher to ascertain. Their experience was the object of the study, therefore their experience was accepted as such. Similarities were present among the experiences of the five women thus it is unlikely that the co-researchers fabricated their experiences.

The mothers, as co-researchers, possessed only their own perception of a very complex issue and the meaning of their experiences was somewhat limited through examination just of their perspective. The perceptions of the mothers was, however, the aim of this particular study. This project provided one perspective and other studies yet to be undertaken would add depth and various dimensions to the experiences of the mothers. Deaf mothers, and parents of deaf children, should also be studied to determine the meaning and context of their experience and to discover if similarities exist among the experiences of parents, whether hearing or heaing impaired. "The experiences can be studied through a multiplicity of points of view...these are not conflicting truths, though the accounts may disagree; they are all a part of the meaning of that experience (Barrit, et al, 1983, p. 143).

Effects of Bracketing Upon Research

This section provides a description and rationale of the biases, preconceptions and opinions that have changed for the researcher. This section involving the effects of the researcher's bracketing upon the research process will be presented in the first person as a component of phenomenological writing (Manasse, 1987).

A series of emotional stages in learning to adjust or accept the child is too linear to describe these womens' experiences and does not thoroughly explain the pain, and frustrations of the mothers with adolescent children. Perhaps the stages of adjustment (Mendelsohn, 1981; Moores, 1982;) describe the first few years during and after diagnosis, and that acceptance and adjustment are the proposed "end products" of the process. The mothers had, in varying degrees, accepted their child's handicap but still continued to have recurring struggles with their emotions and memories. The personal growth and other influential factors such as quality of interactions and support were not adequately explained by the current stage theories. The writing by other parents in the literature, such as Fairchild (cited by Luterman, 1984), Forecki (1985), and Spradley and Spradley (1978) possessed more correspondence to the mothers' experience than some of the research literature.

These mothers have demonstrated their involvement through describing their role as an advocate choosing programs and dealing with professionals and going against the advice of the professionals for and with their children. Prior to this study, I had thought that the parents were often pawns in the power stuggles between professional programs. Instead the parent held much of the decision-making power and these women were all to some degree responsible for the involvement of their children in educational and community programs.

The mothers may have experienced difficulty choosing a communication method and an educational placement due to what is often contradictory information or advice but they nonetheless did decide. Several of the women continued to monitor their children's progess and switched programs for their children until one seemed most suitable.

Commonly in the literature, hearing impaired children experience difficulty with the English language and possibly with communication; except for one adolescent, all of the children, according to their mothers, were proficient with language.

There did not seem to be much, if any, evidence the adolescents had inappropriate social behavior and emotional problems for four of the five children.

The mothers did not describe their children in relation to choosing between the deaf and hearing worlds although one mother mentioned she had to continue learning to respect her daughter's perspective and keep her own "hearing perspective" in check. My presupposition that the children may experience difficulty balancing or choosing the deaf and/or hearing worlds and in moving between the two cultures was not demonstrated by this study. The dea world as viewed by hearing parents and professionals should also be examined.

This study has been a rewarding professional and personal experience for the researcher. I became involved for a short time with five interesting women whose very different experience was nonetheless fascinating. The bracketing was a learning experience because of the increased awareness gained regarding my reactions to the stories the mothers related and my unseen biases that emerged. By becoming aware of my biases and stating them explicitly, I was better able to put them aside to focus upon the experience. Bracketing assisted me to become increasingly alert to and aware of some of the emotions and experiences of the mothers as I,too, felt some of their pain and frustration or their hostility towards certain professional people.

The research process was beneficial to the researcher and to some, if not all, of the mothers. Bracketing of biases, expectations, reactions, and preconceptions lead the researcher to discover deeper meanings and insights. The second interview was crucial to check the culled themes with the co-researchers and to add and modify information and perceptions.

One of the mothers told the researcher that she had found the interview process beneficial, and that the non-judgemental listening by another person improved her every day interactions. All of the mothers were receptive to the researcher and readily discussed their experiences.

The mothers' feedback, regarding their insistence upon anonymity, was an interesting possible effect of the research upon them. It was very disconcerting that the possibility exists that the actions and opinions of the parent can indeed so negatively affect the relationships and services the child might or might not subsequently receive. Another parent and researcher, Fairchild (1980), also noted that while collecting information for a presentation, a father of a deaf child agreed to share his experience with Fairchild provided he remain anonymous. This is unfortunate and needs to be addressed by parents and professionals alike. Without accurate feedback through honest, shared conversations with parents and professionals, systems and services are difficult if not impossible to modify and improve.

Future Considerations

This section contains recommendations by the mothers and the researcher, further illustrated by suggestions from the literature. Recommendations are important to a study because, " research separated from practice is meaningless and practice without research is mindless. Research and practice must exist together in one situation. Where practice is informed by research there is interest, vitality and even wonder. Where research grows out of practice there is involvement, excitement and relevance." (Barritt et al., 1983, p. 150). Suggestions for further research are also discussed.

Having a handicapped child places tremendous strain on relationships. As described by Klein (1984), who is a parent of a handicapped child, parents often isolate themselves from family, friends and colleagues. Support should be available for mothers who have decided to return to the workforce after raising their hearing impaired child and other family members. Strong support groups and counseling for parents, children, siblings, the family unit, and perhaps extended members of the family are needed and must be continuously provided and monitored from a diagnosis of hearing loss. Other persons in the mothers' lives, such as their spouse or partner, grandparents, siblings, friends, and professionals involved with their children or themselves, could be included to add dimensions to further understanding of the mother's experiences.

Effective impartial counseling must be made available by trained professionals as soon as possible and be continuous to assist parents to deal with information, emotions, and their acceptance of their child's deafness. One mother stated that if effective, early counseling had been and was more readily available, fewer family problems such as divorce would occur. Counseling and genetic counseling are suggested by several authors in the literature (Bodner-Johnson, 1980; Carver, 1984; Klein, 1983; Luterman, 1984).

Several mothers recommended that there should be a broadened scope of counseling and education involving siblings and extended members of the family. Parents frequently can identify a problem but because of limited resources cannot implement a solution and therefore need assistance in learning to cope effectively. Often parents do not have much time and energy left for themselves, let alone their other children, and means must be found within the family to share feelings of anger and guilt and to develop opportunities for acceptance and growth.

Support groups for the siblings and possibly for other involved relatives should be created that would focus upon the unique problems and situations of these individuals with a handicapped family member. This would allow guidance, feelings, coping strategies, and information to be provided and shared amongst the members.

One mother stated, "If I could go back I would encourage these people who were trying so hard to do the best for their kids to spend more time with each other and to get sitters other than to go to meetings." Implementing day care and babysitting for the handicapped children and their siblings would allow the parents to spend time with each individual child or with each other and also provide parental relief and leisure time.

The relationships of the spouses and other family members are an important part of their lives and must be treated as such. Families with other handicapped children, hearing impaired first born children or only children could be explored to further illustrate the mothers' varied but often similar experiences. Older and/or younger siblings could also be studied. Mothers and fathers could be studied together and/or separately, as well as similarities examined in single and dual parent homes with a hearing impaired child member.

Several mothers described the benefits of meeting and observing older hearing impaired children and adults. "You had someone to measure progress [against] , to look up to and gauge their success." This assisted the mothers to realize that their children could become well functioning individuals although the problems at hand were great. Longitudinal studies of children from childhood through adolescence into adulthood could be conducted to more fully understand a wider spectrum of experiences as the children mature. A deaf man in the literature described the basic reason for parents to meet and become involved with deaf adults as, "We are your children grown" (Schreiber, 1969, p. 4). Other authors have recommended interaction with deaf peers and adult role models (Carver, 1984; Cohen, 1978). The experiences of hearing impaired parents with hearing impaired children should also be explored.

Parent to parent support groups have provided these mothers with information, personal interactions and a vehicle through which to meet other parents who share similar life settings. One mother said the large and the small parent support group served different purposes. The large group was,"mostly useful for information, like I think it would help a parent of a young kid to see some older kids." The small group she described as, "the way it is working right now is we've got a few, the ones of us that have kids in a certain area are supportive of each other so we have a small support system now, [with] the teachers, too."

This mother explained that because the larger groups are so diverse parents experience difficulties organizing meetings and social events. She suggested that the professionals could perhaps organize the events because they know who the parents are, and how and where to contact them. "It's hard to start with a little group of parents and.. only have a few that are willing to create these social occasions and visit the government...because you're just a parent in all this mob of people, kids and parents."

A facilitating relationship with a concerned professional can greatly assist the parents. Parents and professionals should interact in a caring, respectful and supportive manner. "Some of the professionals would condescend to the parents...as long as I'm treated in an equal manner then I'm fine but if not, I freeze, pull back, get sick, or pull rank such as using teacher language with a social worker and the social worker language with the speech therapist", explained one mother. Increased sharing of information and resources among parents and professionals should occur to ensure both parties are informed and included. Professionals should become involved because, as one mother suggested, "the parents do not always have enough will, energy, or know how to change things." Another mother stated, "It's important the teacher go into the homes; it's effective in that it is in the parents' domain and the teacher is a guest." It has been suggested that parents and professionals should function as a team with each partner possessing specific roles and responsibilities (Taddeo, 1985). Parent-professional relationships should therefore be two specialists interacting, not one.

One mother's strongest criticisms of the parent-professional relationships was that professionals talk rather than listen to parents. Instead professionals must be sensitive to the parents' pain and emotional condition. Professionals should be empathetic to the parent as a person and attempt to determine the parent's position and suggestions through active listening. The needs of parents, and not the biases of uninvolved professionals must be catered to in the relationships of parents and professionals.

Parents, as suggested by the mothers, should be provided with accurate, complete information and straight, honest answers from which to make their choices. Another parent, Klein (1983), stated that parents feel strong resentment toward professionals who hedge or don't tell them the truth, but feel gratitude to those professionals who are honest.

One mother stated that perhaps parents so-called "shopping behavior for professionals" (that is, consulting with a variety of professionals regarding the same 'problem') occurs because the parents are seeking answers and have not received enough appropriate information and answers from any of the professionals. The parents may know or at least suspect there is a problem with their child. She described a situation in which a professional she knew worked effectively with parents of a handicapped child. The professional questioned the parents about behaviors they had observed in their child, then the professional provided information about those behaviors. "The parents already knew the kid was [handicapped] but no one had confirmed their belief...the kid was five years old and could've been in another program." This demonstrates the need for quickly providing appropriate, accurate information to the parents, and utilizing the parents' observations in diagnosis and treatment. Professionals must ensure the parents comprehend the material although the information may be difficult and new. Without complete, accurate information available it is very difficult for anyone to make informed, reasonable, rational, and appropriate decisions.

There is a great need for more properly trained, empathetic and effective professionals and interpreters. Medical, and rehabilitative personnel should have comprehensive education training regarding deafness and should cooperate to eliminate stereotypes and misconceptions. Parents need to be involved in selection of hearing aids and be seen at more frequent intervals over a longer time period (Blair, Wright & Pollard, 1981). Education of parents and professionals is needed to develop more efficient and effective methods of communicating and interacting. The number and quality of parent involvement programs should be increased because, "good parent programs have a snowball effect, they produce self-confident, positively assertive parents who will work as equals with other professionals and they become in effect trainer of other professionals... parents and professionals are natural allies...they both want in the most ardent terms the same thing: a better-communicating child " (Luterman, 1984, p. 157).

Communication that is fluent and two way is important to the development of the person. The methodology through which communication occurs should be the most effective and least inhibitory for those involved. Each methodology has different strengths and weaknesses but the appropriateness of each one is dependent upon the individual circumstances of usage. Children should continue to be monitored in regards to their fluency of communication. A variety of methods should be used to allow the children to utilize the best method for them. The audiogram and other types of factual information are only some of the factors that determine how the children will function using a certain methodology. The professionals must keep in mind that their function is to assist the parents and children, not to advocate one particular methodology. Suggested one mother, "Let the kid embroider the reality on the general guidelines of the audiogram."

As summarized by one of the mothers, "Understanding and communicating are important, not 'how' they communicate." She emphasized that it is not the methodology but the way in which it is presented that is crucial. "It is important to stimulate hearing but restricting input is not good. From the way kids learn you enhance learning through all channels." Two-way fluent communication should be the essential goal. Adults should sign in front of children who are using sign as one mode of communication to enable hearing impaired children to learn that their communication system is worthy and is used in adult to adult conversations.

One mother suggested parents of newly diagnosed hearing impaired children who have chosen a Total Communication methodology learn a sign substitution system to enable them to communicate. Stress is added on parents when they must learn a new communication system at a very emotional time. "So what [if the parents learn a sign substitution system and not American Sign Language] I think if they communicate with their kid that's the most important issue; however, that's probably not a very popular view [because the prevalence of sign classes teach American Sign Language]. The dilemma is how to get parents to be signers fast!" This mother explained that teaching parents a sign substitution system is important. Her rationale for this position is, "One is it's the fastest way for them to learn it and the other is it's important educationally for the kids to develop English...it's stressful for [parents] to learn a sign substitution system which is coming from their mother tongue, let alone a whole other language."

Education services delivered in a wide variety of settings should be available to meet the needs of the hearing impaired children and the people in the children's environment. The children should receive support such as oral or sign language tutors, aides, or notetakers to assist them in succeeding in their educational setting . Alternative programming must be available because of the range of individual needs to which the programs must cater. Within the educational system there should be more movement across and between programs with various philosophies and sharing amongst professionals to ensure the children receive the best education. The effectiveness of programs that involve parents, as well as determining the involvement of parents in the education process from administrative to classroom levels, should be examined.

Means to assess the needs of hearing impaired children and their families, and to decide the most appropriate programs and services need to be established. Instruments are needed that can be used by professionals with parents to ascertain the parent's current level of awareness and adjustment, family members and situation and make practical programming and placement decisions accordingly (Blacher, 1984). According to Klein (!984), the only way a person can know what it is like to be a parent of a handicapped child is to be one. Parents know their own children best as they continue to learn about their children over time. Parents of young handicapped children must piece together a network of services for their child and themselves, often in communities in which services are few and far between. Suggestions by the Task Force Report (Childhood Hearing Impairment, 1984) stated better coordination of services at federal and provincial levels, assessment and placement procedures implemented by provinces, and a clear set of criteria to designate eligibility to receive special educational services are needed.

A variety of factors seem to be involved in determining which methods of communication and education are most suitable for the individual child and her/his family. These factors may include: the child's abilities and interests, that is, if the child exhibits a natural propensity towards one method or other; the quality and support available to the child and parents; the availability of suitable programs; the involvement, expertise and relationships with individual professionals; the functioning of the child in a program; the interaction and involvement of the siblings; auditory and visual alertness; and the involvement of the parent in accessing the programs, funding and professionals. These factors deserve further research to attempt to determine their effect upon the experience of the mothers of hearing impaired adolescents. As well, studies of American Sign Language and sign substitution systems and their effectiveness with parents could be undertaken.

More attention must be paid by researchers, other professionals and parents to well-functioning family units,and effective, adjusted parents and children who have experienced success in some ways. Too often, as suggested by one of the mothers, the "pathology" of the family and the situation are focussed upon.

The mothers in this study are essential components in their children's lives and professionals must learn to respect and effectively utilize mothers, and possibly fathers, in habilitation, development and education of hearing impaired children. Two mothers in this study were encouraged by professionals to keep their children in an oral orientated program and one other mother was strongly encouraged to learn sign language and move her child into a simultaneous communication setting. These parents, however, held firm in their decisions which, in hindsight, were the most suited for them. Parents should learn to take control and make their decisions to the best of their ability because their input is worthwhile.

The importance of the parents must be emphasized in accessing the various services and professionals for their children. Parents are usually the only adults that are continously involved with their children's education and treatment. They have ultimate responsibility for their children yet frequently have limited input and role in the decision-making process. Parents are often thought of as observers in their children's life yet, as was shown in this study, all of these mothers have been involved in supporting, attempting to improve or access services, and teaching their children. Through this ongoing traumatic experience all of these five women have experienced some amount of personal and/or professional growth and are all strong individuals in their own ways. Parents are an obvious source of data and should be active particpants in all parts of the process of planning, decision-making and monitoring their children's programs to the degree which is suitable for each individual parent. The consequences of a successful parent-child relationship and involvement and support by professionals will have long term effects on the development and success of children and of mothers.

Professionals can be of great service as empathetic, caring and knowledgeable people but ultimately it is the parent who must make or fight for the decisions, programs, and services for their children. Parents must be involved in all parts of the decision-making process as the ultimate decision-making member. Let us hope that parents, professionals, lay people and children can learn to more effectively work together to strive to fulfill their lifetime potential.

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Appendix A

DEMOGRAPHIC DATA SHEET

Name: ______________________ Code: ____________

Address: __________________________

Telephone: ____________________ Age: ____________

Level of Education: (please specify): ________________________

Marital Status: Single____; Married _____; Divorced _____; Other______

Number of Children:_________ Ages of children ______________

Do you work outside the home: Yes ____ (full-time ____; part time ____);

No _____

Do you receive educational funding for your hearing impaired child? (if yes, please specify): ____________________________________

What groups, if any, are you involved in for families/parents of hearing impaired children:

____

Age of hearing impaired child: ______________

Degree of hearing loss: Right ear __________ ; Left ear __________

Cause of hearing loss, (if known): ________________________

Date, and child's age, when hearing loss diagnosed: __________ ; ________

Educational program child is CURRENTLY attending: ______________

Preferred method of communication with child: ________________

Comments:____

____

APPENDIX B

CONSENT FORM

I, ______________________________, agree to participate in this parent-interview project by Melanie Morgan, for her M.Ed. thesis, under supervision of Prof. L. Wilgosh and Prof. M.A. Bibby. I understand the interview will be taped and the tapes erased when the project is completed to guarantee confidentiality of my name and personal opinions. The journal will be used only for this analysis and may be returned to me if I so wish. Details of the parent's experience may be changed to ensure the privacy of the individual.

____
Signature

____
Date